

# A STUDY OF CHURCHES AS A SOURCE OF SUPPORT FOR FAMILIES WITH CHILDREN ON THE AUTISM SPECTRUM

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## ABSTRACT

The purpose of this study was to understand the unique role of organized religion as a support system to families who have children with Autism Spectrum Disorder (ASD). Faith communities play a vital role in society and have a theological duty to alleviate the stress of families who have children with special needs and to support healthy adaptation. Delimiting the scope of this study to Christian churches in a mid-size metropolitan area in the South, this project used a case study to understand the level of support one family with a child on the autism spectrum experienced in the churches they have attended. Staff members from the family's church were also interviewed. In addition, this study attempted to find how Christian churches in the area respond to families who have children with a diagnosis of ASD, and to find out through a phone survey to what degree clergy were aware of the issues that surround families coping with ASD.

Case study results showed the family participating in the case study had experienced a non-supportive church as well as two churches that gave support in different ways. The main need this family expressed was the need for respite, which helped decrease the family's stress. Also, it was important for churches to consider the needs of the siblings, not just the child with autism. The results of the church staff interviews showed the family's church designed programs by cultivating close relationships with families in the congregation who had children with special needs. Parents were used as an expert resource. Church staff consulted schools, other churches and parachurch ministries when necessary.

A stratified random sample of 300 churches was chosen for the phone survey, with 125 churches responding. About half of the churches had a child with autism attending. Churches from the wealthiest zip codes, with the largest congregations, and with more than five full-time staff were more likely to have a program for children with autism. Most of the respondents were aware of the characteristics of an ASD diagnosis. Implications for practice and future research were given based on the findings.

**Keywords:**

Autism; Church; Faith Communities; Family Ecology Theory; Social Support; Special Needs; Stress.

## DEDICATION

I dedicate this dissertation to families who have children with a diagnosis on the autism spectrum. It is my hope that this research will help to raise awareness of your daily struggles so that faith communities will increase their ability to reach out to your areas of need.

## ACKNOWLEDGEMENTS

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## TABLE OF CONTENTS

ABSTRACT .....	iv
DEDICATION .....	vi
ACKNOWLEDGEMENTS .....	vii
LIST OF TABLES .....	xiv
LIST OF FIGURES.....	xvi
CHAPTER	
1. INTRODUCTION	
Background to the Problem .....	1
Statement of the Problem.....	2
Rationale for the Study .....	3
Theoretical Framework.....	4
Purpose of the Study .....	5
Significance of the Study.....	5
Research Questions.....	5
Qualitative Questions.....	6
Quantitative Questions.....	6
Overview of Methodology.....	7
Assumptions of the Study.....	8
Delimitations of the Study .....	8
Limitations of the Study .....	8
Definitions of Terms .....	9
Summary of Introduction.....	10
2. REVIEW OF THE LITERATURE	
Understanding Autism Spectrum Disorder.....	11
Social Skills .....	12
Communication.....	13
Repetitive Behaviors and Routines.....	13
Co-morbidity and Sensory Issues .....	13

Role of Religion in Families with Special Needs .....	14
Role of Religion and Autism Spectrum Disorder .....	15
Research on Churches and Children with Special Needs .....	17
Theoretical Framework .....	18
Bronfenbrenner's Ecological Model .....	19
Microsystem .....	19
Mesosystem .....	19
Exosystem .....	20
Macrosystem .....	20
Summary of Bronfenbrenner's Theory of Human Ecology .....	21
Family Systems Theory .....	22
Family Ecology Theory .....	24
The Church's Role in Family Ecology .....	26
Summary of Literature .....	27

### 3. METHODOLOGY

Research Design .....	28
Participants .....	29
Qualitative Participants .....	29
Quantitative Participants .....	30
Instrumentation .....	31
Qualitative Instrumentation .....	31
Quantitative Instrumentation .....	32
Procedures .....	33
Qualitative Procedures .....	33
Quantitative Procedures .....	33
Verification of Results .....	34
Reflexivity Statement .....	36
Qualitative Data Analysis .....	36
Quantitative Data Analysis .....	37
Summary of Study Methodology .....	38

### 4. QUALITATIVE RESULTS

Findings on Research Questions 1 – 4 from Qualitative Analysis .....	39
Research Questions 1 – 2 Results: Impact of Church on Family and Family's	
Perceived Needs .....	40
Family characteristics .....	40
Results on mother's perceived support needs .....	42
Needs at first: Need for a diagnosis .....	42
Needs at first: Financial needs .....	43
Needs at first: Need for guidance .....	43
Needs at first: Need for understanding from family and friends .....	44
Current needs: Need to grieve .....	44
Current needs: Need to surrender and move on with life .....	45

Current needs: Need for a “normal life” .....	46
Current needs: The need to attend church .....	47
Current needs: The need for intimate church relationships .....	50
Current needs: Need for spiritual comfort .....	52
Current needs: Need for respite .....	54
Anticipated future needs: Need for care as Jacob ages .....	56
Results on older brother’s perceived support needs .....	58
David: Need for structure .....	59
David: Need for friendship .....	60
David: Need for respite .....	60
David: Theology of ministry .....	61
Results on younger sister’s perceived support needs .....	62
Sarah: Need for friendship .....	63
Sarah: Need for respite .....	63
Sarah: Need for spiritual comfort .....	64
Results on younger brother’s perceived support needs .....	64
Sam, Jr.: Need for spiritual comfort .....	65
Sam, Jr.: Need for structure .....	65
Sam, Jr.: Need for respite .....	66
Summary of Research Questions 1 – 2 Results .....	66
Research Questions 3 – 4 Results: How Churches Design Special Needs Programs...	68
Church characteristics and history of special needs program .....	68
How the programs were organized .....	70
Results on interview with the special needs coordinator .....	72
Listening to parents .....	72
Ministering to the whole family .....	73
Gathering support from the whole church .....	74
Jacob: An example of how the church meets special needs .....	75
Aimee: Theology of ministry .....	79
Results on interview with the children’s ministries director .....	80
Logistics and leadership structure .....	81
Relying on the expertise of parents .....	82
The value of respite .....	83
Vision for the Future .....	84
Martha: Theology of ministry .....	85
Summary of Research Questions 3 – 4 Results .....	85

## 5. QUANTITATIVE RESULTS

Findings on Research Questions 5 – 9 from Quantitative Data Analysis .....	89
Overview of Study Results .....	90
Descriptive statistics on the populations of churches .....	90
Descriptive statistics on the random sample of 300 churches .....	92
Descriptive statistics on the 125 churches interviewed .....	94

Results for Research Question 5: What Characteristics of Churches Correlate with Providing Programs for Families with a Child who has ASD? .....	99
Results for Research Question 6: What Proportion of Churches has a Child or Children with ASD in their Congregation? .....	102
Results for Research Question 7: How do ASD Prevalence Rates of Attendance in Churches Compare with IDEA Statistics?.....	105
Results for Research Question 8: What Resources are Churches Providing for Families with a Child who has ASD? .....	108
Results for Research Question 9: What is the Degree of Awareness of ASD among Church Staff? .....	108
Summary of Results from Research Questions 5 – 9 .....	113
Research question 5 .....	114
Research question 6 .....	115
Research question 7 .....	115
Research question 8 .....	115
Research question 9 .....	116
 6. SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS	
Summary of Study Focus and Methods .....	117
Purpose of Study .....	117
Summary of Study Literature Review and Theoretical Framework .....	118
Summary of Methods.....	119
Interpretation of Research Findings .....	121
Interpretation of family ecology model using the Smith family .....	121
Interpretation of Research Questions 1 – 2 .....	125
Interpretation of Research Questions 3 – 4 .....	127
Interpretation of Research Question 5.....	128
Interpretation of Research Questions 6 – 7 .....	128
Interpretation of Research Question 8.....	129
Interpretation of Research Question 9.....	130
Limitations of the Study.....	130
Recommendations for Practice.....	131
Recommendations for Future Research .....	133
Summary of Study Findings and Recommendations .....	135
 REFERENCES.....	137
 APPENDICES	
A. INFORMED CONSENT LETTER FOR ADULT INTERVIEWS.....	142
B. ASSENT FORM FOR CHILD .....	144
C. PARENT CONSENT FORM FOR SIBLING INTERVIEWS .....	146

D. PARENT CONSENT FORM FOR OTHER INTERVIEWS.....	148
E. AUDIO TAPE RELEASE FORM .....	150
F. PARENT INTERVIEW PROTOCOL .....	152
G. SIBLING INTERVIEW PROTOCOL .....	154
H. CHURCH STAFF INTERVIEW PROTOCOL .....	156
I. CHURCH DEMOGRAPHIC QUESTIONNAIRE .....	158
J. AUTISM AWARENESS SURVEY .....	162
VITA.....	166

## LIST OF TABLES

5.1	Population of Churches in the Area according to Group.....	92
5.2	Types of Responses to the Phone Survey according to Denomination .....	93
5.3	Types of Responses to the Phone Survey according to Categories .....	94
5.4	Denominational Affiliation from Churches that Participated in Questionnaire .....	95
5.5	Denominational Groups.....	96
5.6	Zip Code Groups .....	96
5.7	Number of Full-time Staff Employed by Church.....	97
5.8	Average Attendance by Group .....	98
5.9	Average Children’s Attendance by Group .....	98
5.10	Attendance of Children with Special Needs according to Church Size .....	101
5.11	Attendance of Children with ASD according to Church Size .....	101
5.12	Types of Formal Training.....	102
5.13	Average Children with Special Needs Attending by Group.....	103
5.14	Types of Special Needs Identified by Churches.....	104
5.15	Frequency of Children Attending on the Autism Spectrum .....	105
5.16	2006 IDEA Statistics for the State of Tennessee.....	106
5.17	2006 – 2007 IDEA Statistics for Davidson and Williamson Counties.....	106
5.18	2006 – 2007 IDEA percentages for Davidson and Williamson Counties .....	107
5.19	Special Needs and ASD Statistics from 2010 Church Questionnaire .....	107
5.20	Types of Modifications for Children with Special Needs .....	108
5.21	Descriptive Statistics for Results of the Autism Awareness Survey .....	110

5.22	Responses to Personal Reflections about Ministry to Children with Special Needs.....	113
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## LIST OF FIGURES

2.1	Model of Bronfenbrenner's ecological theory of development.....	22
2.2	Family ecology model .....	25
4.1	Venn diagram of the Smith family's perceived needs.....	67
4.2	Visual model of church process for meeting needs of families.....	87
5.1	Denominational group according to children with special needs attending .....	99
5.2	Denominational group according to children with ASD attending .....	100
5.3	Distribution of summed scores for the Autism Awareness Survey.....	111
5.4	Low/High scores from autism awareness survey according to zip code group.....	112
6.1	Visual model of family ecology theory .....	119
6.2	The Smith family micro- and mesosystems before ASD diagnosis .....	122
6.3	The Smith family micro- and mesosystems after ASD diagnosis .....	125



## **CHAPTER 1**

### **INTRODUCTION**

Autism not only impacts the development and functioning of a child, but the development and functioning of the entire family as well. Parents of children with a diagnosis of autism face many challenges and stressors. It would seem natural that parents who rely on organized religion, clergy, or members of their local faith community would also depend on these aspects of a faith community for support in a time of crisis. However, some research indicates that the majority of parents of children with special needs do not feel supported by their faith communities, which can add to their distress and isolation (Speraw, 2006). This study explores one family's experience with faith communities in light of their son's diagnosis of Autism Spectrum Disorder in order to understand the unique role of a faith community in supporting a family who has a child with autism.

#### **Background to the Problem**

Autism was once thought to be quite rare, but has dramatically increased in prevalence to the current level of 1 in 110 (Centers for Disease Control and Prevention, 2009), or perhaps even 1 in 91 live births (Kogan, et al., 2009). This means more families than ever are coping with a child who has a diagnosis of autism.

Parents of children with any type of disability are prone to higher rates of stress than parents in the general population (Miller, Gordon, Daniele, & Diller, 1992). However, parents

with children on the autism spectrum report higher rates of depression and anxiety than parents of children with other types of disabilities (Bromley, Hare, Davison, & Emerson, 2004). These higher rates of psychological distress were associated with lower levels of support because the behaviors of these children were so challenging. The communication impairments, disruptive behaviors, and tantrums associated with autism created difficulties in managing such a child on a daily basis. These behaviors tied up the parents' time and made it difficult for them to rely on others for respite. In addition, these parents also often faced institutional battles for proper treatment and education of their children, taxing emotional and financial reserves (Rodrigue, Morgan, & Beffken, 1990).

Some families with children with special needs find ways of coping to mediate the stress they experience, by forming support networks with friends as well as community institutions (Twyo, Connolly, & Novak, 2007). This includes experiencing a positive connection with their spiritual beliefs and organized religious community (Selway & Ashman, 1998). But there is a lack of published research in the area of churches and autism. No study has yet explored the prevalence rates of families who have children with autism in congregations. No research has delineated how many churches or faith communities offer programs and ministries to affected children and their families, or if churches are even equipped to provide such ministries. And no studies have been done to explain the characteristics of churches that do offer such programs and ministries, or which programs are most effective for churches to use.

### **Statement of the Problem**

Children with Autism Spectrum Disorder (ASD) have particular developmental impairments that place extreme amounts of stress on families and deplete their resources and ability to cope. These families rely on community agencies and institutions to assist them in

copied with their struggles and challenges. For many families this includes their faith tradition and organized religion. Several studies have indicated families who have a child with ASD feel isolated and excluded from their faith communities (Speraw, 2006). Sufficient research has not been done to see if clergy are aware of the growing rates of ASD or whether congregations are mobilizing to meet the needs of these families.

### **Rationale for the Study**

Having a child with ASD places a high degree of stress on a family (Bromley, Hare, Davison, & Emerson, 2004; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). A contributing factor to this stress is that these parents tend to be isolated from their support networks (Gray, 2006; Woodgate, Ateah, & Secco, 2008). Communication problems and disruptive behaviors add to the level of isolation for parents and families of children with ASD (Wulffaert, et al., 2009).

Community institutions such as schools and churches help to mediate stress levels by providing support (Treloar, 2002; Tway, Connolly, & Novak, 2007). The networking potential in these institutions decreases social isolation and provides a sense of belonging (McNair & Smith, 1998). Therefore, more research needs to be done to determine what churches are providing for families who have a child with ASD.

This study explored the experience of one family with a child on the autism spectrum and their relationship with several churches. In addition, a sample of churches in a mid-size metropolitan area was surveyed for information regarding children on the autism spectrum in their congregations.

## Theoretical Framework

This project relied on family ecology theory for its theoretical framework. Family ecology theory joins concepts from family systems theory with Bronfenbrenner's human ecology model of child development (Bubolz, 1993). Family ecology theory's perspective on how families influence and are influenced by the institutions in their environments is well-suited for research that focuses on the interaction between churches and families that have children with special needs. Bronfenbrenner's ecological model explained how the interactions between a child and his/her environment shaped the *child's* development. In family ecology theory, the *family* is the center of the model. Family ecology theory looks at Bronfenbrenner's model through the lens of family systems theory, by placing the *family* at the center of the model.

Family ecology theory recognizes that community agencies and institutions have the opportunity to assist *families* of children with special needs, not just children alone. Churches, synagogues, mosques, and other faith communities have a responsibility to help maintain positive relationships/connections in with families, particularly with those that have a child with challenges such as ASD. According to family ecology theory, families of children with ASD who receive support from their faith community should experience an increased ability to cope and lower levels of stress than those who do not. This study sought to understand how effectively Christian churches are fulfilling this key role in the ecology of family life for those with children on the autism spectrum. In addition, this study sought to understand the impact that a supportive and/or non-supportive church can have on functioning of a family who has a child on the autism spectrum.

### **Purpose of the Study**

The purpose of this study was to understand the unique role of organized religion as a support system to families who have children with ASD. Faith communities play a vital role in society and have a theological duty to alleviate the stress of families with children with special needs and support healthy adaptation. Delimiting the scope of this study to Christian churches in a mid-size metropolitan area, this project sought to understand the level of support one family with a child on the Autism Spectrum experienced in the churches they have attended. Also, this study attempted to find out to what degree clergy were aware of the issues that surround families in coping with ASD, and how Christian churches responded to families who have children with a diagnosis of Autism Spectrum Disorder (ASD).

### **Significance of the Study**

By conducting this study, the author hoped to identify specific ways that Christian churches were (or were not) supporting families of children with ASD. This information has the ability to raise awareness of ASD in churches and promote further research in how they can best provide for their members. This study sought to support conversations among religious organizations, professionals from agencies that serve children with special needs, and the families themselves on the importance of faith traditions and community support for families with children who have special needs.

### **Research Questions**

The central question of the case study was, “What types of support does a typical church provide to the family when one of its members has been diagnosed with ASD, and what is the impact of this support on the family?” This question gave an opportunity for both positive and

negative experiences to be shared, and provided an opportunity to develop ideas on how faith communities provide support to special needs families who are dealing with the stress of their child's diagnosis. To answer this central question, the author used a combination of qualitative and quantitative methods to analyze the study's research questions. Qualitative questions generated data relevant to experience and process. Quantitative questions generated data that could be transformed into statistical analysis.

### **Qualitative Questions**

In order to understand how a church influences the ecology of a family with a child diagnosed on the autism spectrum, questions were asked of a family and church staff that revealed personal experience and personal perspective (Creswell, 2009). These questions were:

1. What types of support is an ASD parent looking for from their church?
2. What kinds of impact does a family's relationship with its church have on its ability to cope with the stress of having a child with ASD?

In addition, questions were asked that revealed the process of awareness and designing programs:

3. By what process does a church become aware of the need to support families who have children on the autism spectrum?
4. By what process does a church design programs to support families with a child who has ASD?

### **Quantitative Questions**

Research questions were asked that could be analyzed statistically.

5. What characteristics of churches correlate with providing programs for families who have a child with ASD?
6. What proportion of churches has a program specifically to support families of children with ASD?
7. How do ASD prevalence rates of attendance in churches compare with regional and state IDEA statistics?
8. What resources are churches providing for families who have a child with ASD?
9. What is the degree of awareness of ASD among church staff?

### **Overview of Methodology**

In order to answer the above research questions, this study used a mixture of qualitative and quantitative methods. Qualitatively, the researcher identified a case study family from Midtown Reformed Church (a pseudonym) in a mid-size metropolitan area in the south. This church has an effective and growing ministry to families who have children with a diagnosis of ASD. The researcher conducted a series of semi-structured interviews with a family who has a child with ASD. In addition, church staff participated in the interviews. These interviews sought to reveal the experiences and perspectives of all persons in the case study, as well as to uncover the process of providing supportive programs in a local church.

Quantitatively, the researcher surveyed a stratified random sample of Christian churches in the metro area. The survey gathered demographic information (attendance, denomination affiliation, types of programs offered for children with ASD, etc.). In addition a Likert scale questionnaire was given to church staff to assess their level of knowledge on the autism spectrum.

### **Assumptions of the Study**

The following were some assumptions that were made in this study. The researcher assumed that the majority of churches would volunteer to participate in the questionnaire. Furthermore, the researcher assumed church representatives would give thoughtful, truthful and accurate information. It was expected that churches would have access to information pertinent to this study (i.e. information about autism through the media).

### **Delimitations of the Study**

The case study was delimited to one family with a child who shows extreme sensory sensitivity, language impairment and behavioral challenges. Though knowledge of what all faith traditions offer would be very useful information, this project investigated only Christian churches in order to narrow the scope of this study. Information from Christian churches was obtained from churches located in a mid-size metropolitan area in the South through a phone survey.

### **Limitations of the Study**

The limitations of a study are areas which could lead to inconsistencies in replicating the study, as well as difficulties in verifying accuracy (Creswell, 2007; Ritchie & Lewis, 2003). The limitations of this study are as follows:

1. The study was conducted by only one person. Therefore interpretation of the qualitative aspects of the results may be subjective.
2. The qualitative portion of this study was conducted on only one family. Therefore, there could be a concern about generalizing the results to other families (Ritchie & Lewis, 2003). The results of this study should be compared to other studies to assess whether or



not the findings have transferability to other families (Corbin & Strauss, 2007; Ritchie & Lewis, 2003).

3. The questionnaire and survey used in this study were designed for this project and have not been tested for reliability. Therefore, the answers may not produce reliable results.
4. Respondents to the questionnaire and survey may have wanted to present information about themselves and their churches in the most positive light, gloss over inadequacies, or give inaccurate or false information.
5. Smaller churches were underrepresented because some of them only had answering machines and could not be contacted.

### **Definition of Terms**

1. AS – Autism Spectrum
2. ASD – Autism Spectrum Disorder. A neurological disorder that manifests impairments in the domains of social skills, communication, rigidity of routines, co-morbidity and sensory issues.
3. Echolalia – Repetition of words or phrases
4. FET – Family Ecology Theory. A family focused ecological systems theory.
5. GST – General Systems Theory
6. IDEA – Individuals with Disabilities Educational Act
7. Large churches – Between 501 and 1500 members
8. Medium churches – Between 101 and 500 members
9. Mega churches – More than 2000 members
10. Reformed theology – Theology influenced by John Calvin and dates from the 16<sup>th</sup> century

11. Small churches – Less than 100 members

12. Spectrum disorder – Disorders that are presented as a continuum of closely related behaviors or symptoms.

### **Summary of Introduction**

More families than ever have a child with a diagnosis on the autism spectrum. The behaviors and communication challenges associated with ASD result in high levels of stress for families who are coping with a child who has special needs. Churches and other communities of faith have a unique role in providing support and spiritual meaning for these families. However, sufficient research has not been done to determine if churches are equipped to meet the needs of children with ASD. Research has not been done to determine what kinds of support families would like to receive from their faith communities.

## **CHAPTER 2**

### **REVIEW OF THE LITERATURE**

This research study reviewed literature from various bodies of knowledge in order to gain a better understanding of how Autism Spectrum Disorder (ASD) impacts families and faith communities. First, research on ASD is reviewed from a medical and psychological perspective. Next, psychological and social work research is reviewed for information on social support systems. Then, information was gathered from religious and theological studies on the role of faith communities in meeting the needs of families with children who have developmental delays, such as ASD. Finally, an explanation of the theoretical framework is included.

#### **Understanding Autism Spectrum Disorder**

Scientists have not reached a consensus for the dramatic increase in autism diagnoses over the past three decades (Waterhouse, 2008). However, possible explanations for this increase can be found in the following areas. First, some doctors think that prevalence rates were under-reported in the 1970s due to a lack of understanding of the disorder (Heussler, et al., 2001). Also, autism has received a great deal of attention in the media, which has raised awareness of doctors, parents, and educators to early warning signs (Waterhouse, 2008). In addition, there have been changes in how autism is diagnosed, which now includes children who in the past may not have been considered autistic (Gernsbacher, Dawson, & Goldsmith, 2005; Hertz-Picciotto & Delwiche, 2009). Furthermore, there could be changes in the gene pool or environmental triggers that have caused this increase (Hertz-Picciotto & Delwiche, 2009).

Autism is a complex disorder related to abnormalities in the development of brain structure and neurological function (Kabot, Masi, & Segal, 2003). Current research points to a genetic cause, with a 60 % concordance rate for identical twins, and a recurrence rate of up to 8% in siblings (Bailey, et al., 1995; Muhle, Trentacoste, & Rapin, 2004). However, the cause of the genetic abnormalities has not been made clear and autism's etiology could find its origin in yet unexplained environmental causes (Inglese & Elder, 2009; Kabot, Masi, & Segal, 2003).

While some children present a noticeable impairment from early infancy, many children with autism appear to develop along a normal trajectory until 15-18 months of age. Around that time, affected children gradually begin to lose developmental skills gained, such as language, joint attention and playing with toys. A diagnosis is typically made between the ages of two and three (American Psychiatric Association, 2000; Karande, 2006). Autism is now viewed as a spectrum disorder, (Kabot, Masi, & Segal, 2003) where clusters of closely related symptoms are presented on a continuum. These symptoms range in severity from mild to profound. Autism Spectrum Disorder (ASD) symptoms are manifested in five developmental domains: social skills, communication, repetitive behaviors and routines, co-morbidity, and sensory issues. Some of these domains overlap and a child with a diagnosis of ASD may or may not have symptoms present in each domain (Centers for Disease Control and Prevention, 2009).

### **Social Skills**

Social impairments include avoiding eye contact, not wanting to be touched or cuddled, an inability to engage in pretend play, and an inability to share enjoyment or experience emotions from another person's perspective. Children with ASD often engage in stereotypical behaviors such as hand-flapping, toe-walking and excessive laughter for no apparent reason (Centers for Disease Control and Prevention, 2009).

Children with ASD have difficulty understanding social cues, such as making eye contact, reading facial expressions, and body language. These impairments can leave children with an inability to begin or participate in a conversation. Children with ASD can often display disruptive behavior (yelling, crying, screaming, and physically acting out), which makes it difficult to incorporate them into family outings and classroom routines (Centers for Disease Control and Prevention, 2009).

### **Communication**

Impairments in communication may include deficits in receptive and expressive language. These children may not comprehend verbal and non-verbal requests; they may not speak; they may engage in echolalia (echoing back what they have heard), or they may talk in stilted, robot-like tones. The previously mentioned lack of social cuing creates difficulty for these children to pay attention to and interpret gestures, body language, voice inflections and facial expressions (Centers for Disease Control and Prevention, 2009).

### **Repetitive Behaviors and Routines**

Children with ASD often exhibit a rigid adherence to their routines. Varying from a routine may result in a “meltdown” tantrum. Some children with ASD display obsessive interests in certain topics (such as butterflies, or Egyptian hieroglyphics) and have difficulty paying attention to other necessary aspects of learning (Centers for Disease Control and Prevention, 2009).

### **Co-morbidity and Sensory Issues**

A diagnosis on the autism spectrum is often accompanied by mental retardation (75%), and epilepsy (7% - 14%) (Karande, 2006). ASD is also often associated with ADHD,

impulsivity, aggressive behaviors, self-injurious behaviors, tantrums, and poor sleeping habits. These children often display hyper-sensitivity to sensory input (light, sound, and touch) that may be painful or excessively distracting. These sensory issues can bring on disruptive behaviors and inhibit learning (Centers for Disease Control and Prevention, 2009).

### **Role of Religion in Families with Special Needs**

There is consistent evidence that spiritual beliefs and religious practices play an important role as a coping strategy in times of stress (Selway & Ashman, 1998). The use of prayer, theological beliefs, and church attendance has been noted as sources of support for parents of children with a disability (Bennett, Deluca, & Allen, 1995; Selway & Ashman, 1998; White, 2009). Parents who expressed a high degree of religious connectedness to their church experienced a higher degree of positive adjustment in their families (Rogers-Dulan, 1998). These parents attended churches that provided opportunities for socialization and participation in the faith community for their developmentally delayed children. This care and attention to the children made parents feel personally supported by their church.

In a qualitative study, Treloar (2002) surveyed 30 evangelical Christian parents of children with various disabilities. She found that when parents received help and assistance from their church, it promoted positive family adjustment. Parents were able to question God, the nature of sin and guilt, and come through their crisis with a sense of thankfulness and joy. These parents reported their faith was strengthened and deepened through their experiences with their children.

In 2004, Poston and Turnbull conducted a more in-depth qualitative study of 78 parents of children with a developmental disability. The authors conducted focus groups and a limited number of individual interviews in three U.S. cities (Kansas City, Kansas; New Orleans,

Louisiana, and Granville County, North Carolina). Results showed that religion played a major role in the lives of these families. Most parents expressed faith in God and used prayer as a way to connect with God. For these parents, their faith aided them in making sense of their child's disability. However, only about half of the parents attended organized religion or churches. And about half of the parents reported difficulties with churches accepting their child. Understandably, this caused distress for these families.

Speraw (2006) reported similar results in a qualitative study of 26 parents and caregivers of children with disabilities in the southeastern United States. She found that while religious tradition played a critical role in the daily lives of these families, the majority of parents and children felt marginalized within their faith communities. From her detailed interviews, the author identified key themes. These parents expressed the belief that their children had a connection with God and longed for their children to be participants in the faith community. However, parents felt the clergy and congregation at times devalued or did not recognize this connection. A total of 51 religious institutions had been visited or joined by these families in search of an open and accepting faith community. The majority of parents had negative experiences with clergy and congregations, and had experienced distress and a crisis of faith.

### **Role of Religion and Autism Spectrum Disorder**

The limited amount of research specific to autism and religion indicates that families with children on the autism spectrum may rely on a faith community for support, but not find an organized religious congregation in which to participate. A 2005 study of families with a child on the autism spectrum in northern California found that while 83% of parents identified their faith in God as a coping mechanism, fewer than half attended church services (Luther, 2005). A survey of families who have a child on the autism spectrum in the California Bay area (Twy,

Connolly, & Novak, 2007) found that about half of the respondents reported faith in God. However, these families had lower rates of seeking out spiritual support and participating in organized religion than the general population. In a mixed methods study of the impact of autism on families in Ireland, Coulthard and Fitzgerald (1999) found that 66% of parents used prayer, and personal spiritual beliefs as a source of comfort in coping with issues surrounding their child. Furthermore, the authors found a significant relationship between strong personal spiritual beliefs and health status. Those with higher scores on religious beliefs and prayer had better health. However, the majority of these parents did not find support in their local church. Only seven percent of respondents reported that the clergy was helpful when their child was diagnosed with ASD. And 79% said they would not seek help from the church with their problems. Parents reported that autism had isolated them from the church.

In a more comprehensive mixed methods study, Tarakeshwar and Pargament (2001) found 81% of ASD parents expressed that God had given them strength. About 40% of the parents looked to their clergy for support, but 30% felt abandoned by the church. Those who had positive religious experiences scored lower on measures of stress, and those who had negative religious experiences reported higher amounts of depression and anxiety. Thus, when the church is supportive, it is a source of strength to the family, but when it is non-supportive it creates more coping problems for these families.

A more recent descriptive study on parents' views regarding their children with autism attending Sunday school found that mothers described barriers in attitude, communication, and programs in their churches (Howell & Pierson, 2010). All the parents reported that their child with autism enjoyed attending church, but not all parents felt their child was welcomed.



## **Research on Churches and Children with Special Needs**

The church is a natural support provider and is based in the community. Faith communities have traditionally offered a sense of belonging, provided meaning, and decreased a person's sense of isolation in a time of crisis. However, very little research has been done to see how this applies to families of children with autism or to see what churches offer to families of special needs. No studies have been conducted on the level of awareness of ASD in churches, or the number of families with a child on the autism spectrum that can be found in a local church.

In 1977, Gnagy, Satterwhite, and Pless surveyed a random sample of 300 clergy of Christian churches in an upstate New York county. The authors sought to find the level of awareness and programs that churches offered families with chronically ill children (this included children with developmental disabilities). They found that clergy most often were not aware of the issues that surround families with children with special needs. Out of 127 pastors, only 38 responded that their congregation had a child with special needs. The authors were disturbed by these findings. While some clergy did address the needs of such members through spiritual counsel, social networking and advocacy, their numbers were few.

In a similar study McNair and Swartz (1997) conducted a mail-in survey of churches in the area surrounding Los Angeles County. Out of 421 churches, 69 responded, and 56 (82%) of these churches were attended by individuals with disabilities. These churches provided support for their special needs families through distributing food, providing transportation, offering opportunities for service, and providing social/emotional support.

A 2002 survey of the Church of Scotland (Flint, Atkinson, & Kearns, 2002) found that a majority of their congregations are involved in providing support to individuals with special needs. These congregations partnered with local agencies, charities and community

organizations. They provided support services and social events for special needs families. The authors found that the majority of congregations also were involved in inviting and welcoming people with special needs, encouraging their attendance at regular services (Flint, Atkinson, & Kearns, 2002). However, no specific mention was made of autism and the challenges of adapting services and programs to children with profound communication and behavioral issues. A 1999 survey of children with ASD in Ireland found that the churches to which participants belonged generally did not have an outreach to families with children on the autism spectrum (Coulthard & Fitzgerald, 1999). More research needs to be done on this subject (McNair & Smith, 1998)

### **Theoretical Framework**

This project relied on Family Ecology Theory (FET) for its theoretical framework. Family ecology theory joins concepts from family systems theory with Bronfenbrenner's human ecology model of child development (Bubolz, 1993). FET's perspective on how families influence and are influenced by the institutions in their environments is well-suited for research that focuses on the interaction between churches and families with children who have special needs. Bronfenbrenner's ecological model explained how the interactions between a child and his/her environment shaped the *child's* development. In FET, the *family* is the center of the model. Family ecology theory looks at Bronfenbrenner's model through the lens of family systems theory, by placing the *family* at the center of the model.

Family ecology theory is considered a subset of Bronfenbrenner's human ecology theory of development (Moore, 2008). Therefore it will be necessary to further explain Bronfenbrenner's model. In addition, family systems theory will also be explained so the reader can understand how the two theories combine.

## **Bronfenbrenner's Ecological Model**

Bronfenbrenner believed a child's development occurs within a complex system of relationships in the different environments that surrounds the child. He grouped these relationships into four levels (Bronfenbrenner, 1979), and he envisioned these levels as nested within each other, like a set of Russian dolls, or as concentric circles of progressively more distant relationships (Bronfenbrenner, 2005). The four levels were named as follows: microsystem, mesosystem, exosystem, macrosystem. The relationships within these levels are bi-directional, meaning the environment influences the child, but the child also influences the environment. The child, therefore, is an active participant in his/her development not just a passive recipient, and the relationships within these levels could both help and hinder development (Bronfenbrenner, 1979).

**Microsystem.** The microsystem is composed of the settings that are the most proximal to the child. Home, school, church, day care, the neighborhood, or any other setting where the child directly attended are included in this level (Bronfenbrenner, 1979). Some of these settings last a lifetime and others are temporary.

**Mesosystem.** The mesosystem is comprised of the web of connections or relationships between and among the settings in the microsystem. For example, the child attends school and establishes a relationship with the teacher. The parent and teacher establish connections with each other. This triangle of relationships, (the child, parent and teacher) works together to influence the child's development. Suppose the teacher-child relationship reveals the child was having difficulty keeping up with school assignments. The teacher then would rely on the connection made with the parent to call a meeting and discuss the academic issue. Perhaps the

result of this meeting would be to establish a connection with a local optometrist to discover the child needs glasses to correct a vision problem. That is how the mesosystem works.

The mesosystem also could contain negative experiences where breakdowns in the connections between persons push development off track. In the above example, if the parent was unable to meet with the teacher, then the child's academic difficulties would grow. The broken connection would have resulted in the child continuing to struggle with her vision without the correction of eyeglasses.

The child is an active participant in this process. The child shapes her development either by wearing, or even by refusing to wear the glasses. Her choice influences the connections and relationships that surround her.

**Exosystem.** The exosystem contains settings where the child is not present but which may directly impinge on the child's development. Settings such as the parent's work place, city hall, local businesses, and even governmental policies, are arenas that the child may never attend; even so, they have an influence on the child's development. For example, perhaps the parent in our example was unable to meet with the teacher due to long hours at work. These long hours may have been required because the economy was depressed, and the problems in the economy may have been the result of governmental policies enacted at the federal level.

**Macrosystem.** The macrosystem contains the norms, rules, values and beliefs that connect the micro-, meso-, and exosystems. Another word for the macrosystem could be 'culture' or 'society.' Shared culture enhances all the relationships and connections throughout the model. Conflict and broken connections occur when parts of the micro-, meso- and exosystems do not share the same norms, rules, values and beliefs. To continue the above

example, an expected norm is that the child will attend school. To refer again to the example above, a shared cultural value is the importance of education and the belief that children should do well in school. This overarching value is shared by institutions and governmental policies in the exosystem, the web of relationships in the mesosystem, and settings in the microsystem.

### **Summary of Bronfenbrenner's Theory of Human Ecology**

To summarize, Bronfenbrenner's ecological theory views child development through the lens of social relationships in the child's surrounding environments. The quality and quantity of the bi-directional relationships can both help and hinder the child's growth. This model focused on four levels of environments: the settings in the microsystem, the web of relationships in the mesosystem, the institutions and policies of the exosystem, and the overarching culture of the macrosystem. As an active participant in his or her development the child influences and is influenced by each of these four levels. See Figure 2.1 for a model of this theory.

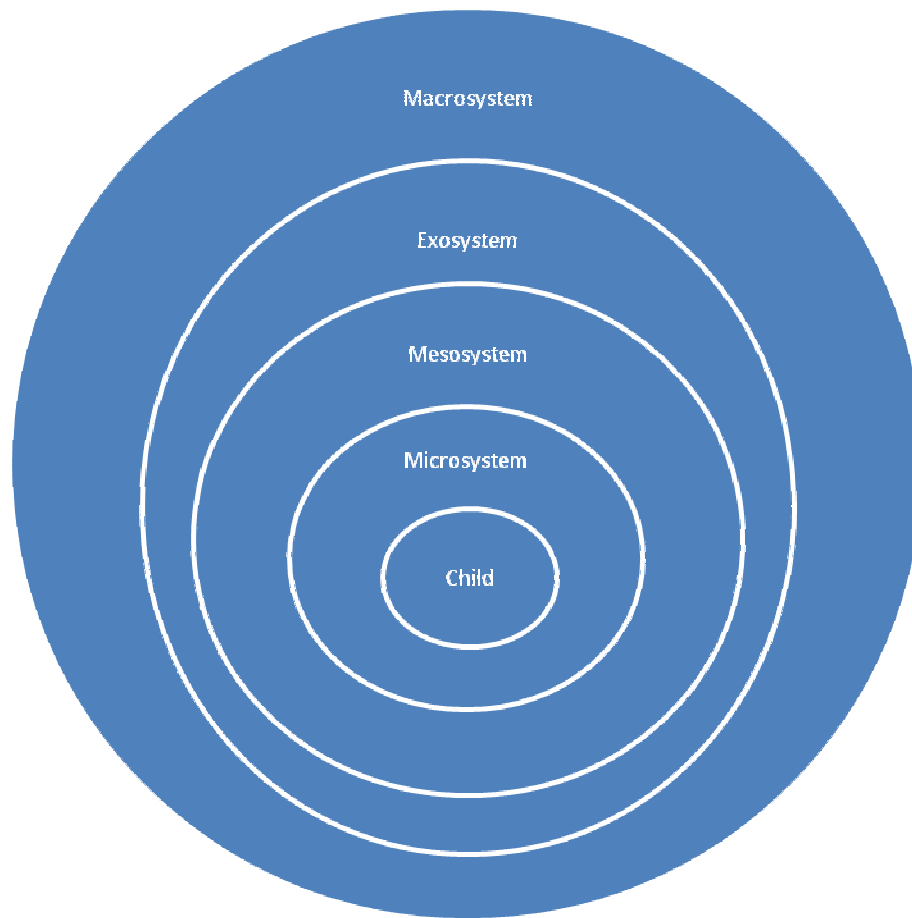


Figure 2.1 Model of Bronfenbrenner's ecological theory of development

### **Family Systems Theory**

Family Systems Theory is characterized by several concepts from General Systems Theory (GST). GST was developed in the middle part of the 20<sup>th</sup> century as a reaction to the prevailing scientific mind-set that to understand something, it must be reduced to its smallest parts (von Bertalanffy, 1969). Rather, GST focused on how different parts interacted with each other to form a whole. In addition, GST was an attempt to unify the various branches of science by noting the concepts and organizational principles that supported both the hard sciences (such as physics and biology) and the soft sciences (such as sociology and psychology) (von

Bertalanffy, 1969; Wade, 2005). Five main concepts from General Systems Theory have provided a framework for Family Systems Theory: *holism*, *complexity*, *adaptation*, *interaction* and *organization* (Breunlin, Schwartz, & Kune-Karrer, 1992; Bronfenbrenner, 1979; Bubolz, 1993).

Families are *holistic* entities. Holism was a response to reductionism (Heylighen, 1992). Instead of focusing on separate parts or components, holism looks at how the components or parts join together to form a whole. For example, a reductionist would break down an automobile into its smallest possible parts in order to understand it. Someone with a holistic approach would be interested in viewing the automobile as a whole and would focus on the way all the parts work together to form a car. In the same way, a family cannot be understood well by only looking at each of the individual members in isolation. A holistic view is required to see the complexity of the individuals' interactions with each other.

Families are *complex* and *adaptive*. In complexity, they are made up of different individuals and form layers of multiple interconnections. They create a wide range of diverse templates (Bubolz, 1993). A family can be formed with or without marriage, with or without blood kinship, with any number of parental figures, and in a variety of economic/financial situations. Families are adaptive; they have the capacity to change and learn from experience. Adaptation can result in both positive and negative change.

Families are *interactive* and *organized*. A change in one person affects the functioning of everyone else, which in turn has an effect on the person who introduced the change. For example, if a man and woman conceive a child, they are transformed into parents, with new roles and responsibilities. They, in turn, influence the development of their child, and so the interactive, recursive natures of these relationships continue for a lifetime. Families are

organized to meet the need for survival, whether biological survival or social survival. A family's primary responsibility is to make decisions on how to best meet the family's needs. This may or may not represent what is best for each individual member.

In summary, family systems theory focuses on the interrelatedness, connectedness, and interdependence of all the individual members who make up a family (Breunlin, Schwartz, & Kune-Karrer, 1992). This perspective is bi-directional. A change in one part of the system affects all parts of the system. For example, a child with a developmental disability would affect the roles, responsibilities, and functioning of the entire family.

### **Family Ecology Theory**

Bronfenbrenner's theories were heavily influenced by systems theory (Bronfenbrenner, 1979; Bubolz, 1993). Therefore it is a natural extension of the four layers of his model to discuss the growth and development of a family (Bubolz, 1993). Other scholars have developed a blend of Bronfenbrenner's model and family systems theory in regards to children with disabilities (Lloyd & Rosman, 2005; Sontag, 1996); however, their theories remain child-focused. The framework of family ecology theory provides a strong rationale in which to study the interaction between families with special needs and churches.

Family Ecology Theory (FET) viewed Bronfenbrenner's model from a family systems perspective by placing the family at the center of the model instead of the child (Bubolz, 1993). In doing so, FET acknowledged the larger aspects of the environment and how these aspects influence and shape development. Relationships outside the family can assist in mediating stress (or increasing it) and can promote positive (or negative) development when families are undergoing stressful experiences that tax their economic, emotional, and physical coping reserves. Thus, family ecology theory sees relationships as recursive and bi-directional, as



assistance from proximal institutions, in turn, has an effect on children with special needs (Andrews, 1980; Bubolz, 1993). See Figure 2.2.

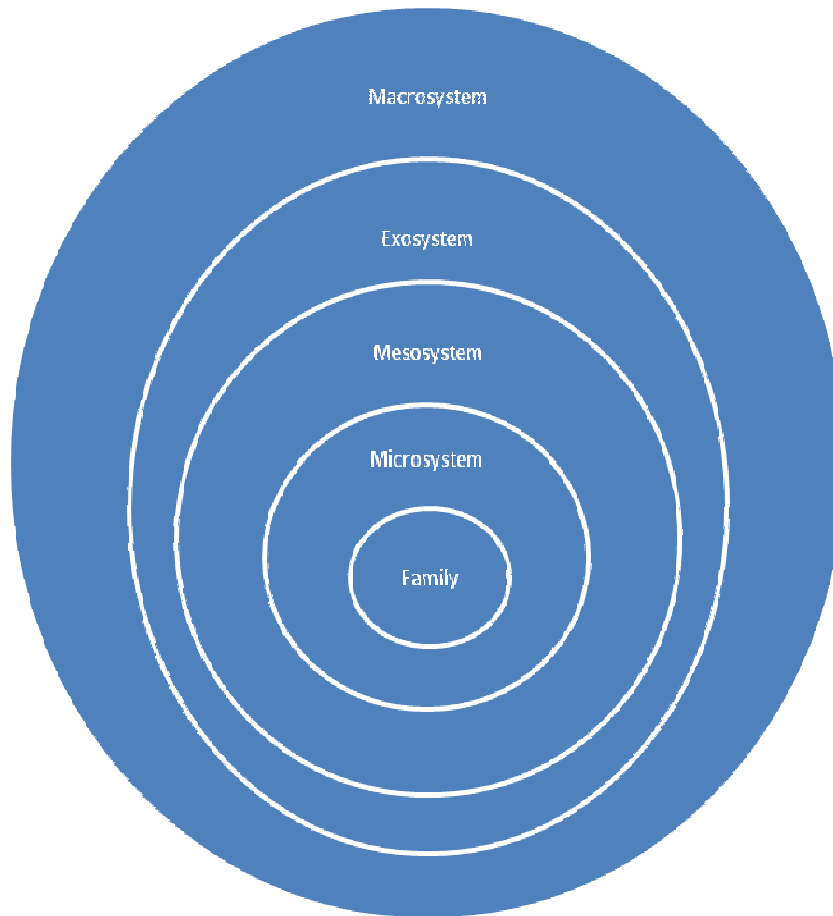


Figure 2.2 Family ecology model

Parents and siblings shoulder most of the burdens and challenges that come from living with a child who has special needs. The family members develop patterns of interacting that mutually shape everyone involved (Breunlin, Schwartz, & Kune-Karrer, 1992). A child with disruptive behaviors may discourage the parents from going out in public as a family. This reinforces the parents' isolation from resources and relationships in the mesosystem, and

decreases the opportunities for a child with ASD to become familiar with new places and situations in the microsystem.

Children with ASD are dependent upon their families and community institutions to provide treatment to lessen their impairments. The most proximate forces have the greatest effect, beginning with the family, extended family, school, church and other community agencies in the microsystem (Cole & Cole, 2001). Schools either help and/or hinder family functioning by the services they do or do not provide for the child. A family that has previously relied upon a church for spiritual and social support may either be strengthened or isolated depending on the church's response to the family.

### **The Church's Role in Family Ecology**

Community agencies and institutions in the microsystem have the opportunity to assist *families* of children with special needs, not just children alone. For those interested in how churches relate to their surrounding communities, the question arises; are churches adjusting their programs to accommodate families who have a child with ASD? Religious issues are essential to any study of the family (Lloyd & Rosman, 2005). However, very little research has been done to find out what organized religion and faith communities are doing to connect with special needs families, particularly families with children on the autism spectrum.

Churches, synagogues, mosques, and other faith communities have a responsibility to help maintain positive relationships/connections in the mesosystem with families, particularly with those that have a child with challenges such as ASD. According to family ecology theory, families of children with ASD who receive support from their faith community should experience an increased ability to cope and lower levels of stress than those who do not. This study sought to understand how effectively Christian churches are fulfilling this key role in the

ecology of family life for those with children on the autism spectrum. In addition, this study sought to understand the positive and/or negative impact a church can have on the functioning of a family with a child on the autism spectrum.

### **Summary of Literature**

In summary, personal faith and participation in organized religion is important for many families who have children with disabilities. When these families have positive experiences with their faith communities, they experience a greater degree of positive adaptation to the challenges of raising a child with special needs. However, when these families are isolated, ignored and left out of their faith communities, they experience increased psychological distress. Very few studies have been done on what types of support churches provide for special needs families. The few studies that exist indicate churches have a lack of awareness of the issues surrounding special needs families. Families with children who have ASD pose particular challenges for faith communities. In addition, no studies have been found on the particular challenges that families who have a child on the autism spectrum pose for faith communities, or how organized religion embraces the increasing number of families with children of autism. Clearly further research is needed to understand how churches can embrace and support these families.

## **CHAPTER 3**

### **METHODOLOGY**

The central question of this study is, “What types of support do churches provide when a member is diagnosed with ASD and what is the impact of this support on the family?” In order to answer this question, this research project primarily used a case study format to reveal one family’s experience finding a church to attend with their son, who has ASD. In addition to the case study, churches from a mid-size metropolitan area in the south were surveyed for data on church characteristics that correlated with ASD programs, types of programs offered, prevalence rates of attendees who had children with ASD, and the level of understanding clergy or church staff had on ASD. Qualitative data from interviews were subjected to content analysis techniques and quantitative data were analyzed using non-parametric tests. Issues of verification of research are discussed in this chapter as well.

#### **Research Design**

To answer the central question of how churches respond when a member is diagnosed with ASD and to understand the impact this support has on families, this study proposed a descriptive design, using a mixed methods approach: a case study of one family coupled with a phone survey of churches in a mid-size metropolitan area. The nature of an instrumental case study allowed the researcher to use one bounded case to exemplify a particular issue (Creswell, 2007). The use of a bounded design was intended to provide a more in-depth explanation than could be offered through quantitative measures alone. The context that bounded this case study

was autism, with particular attention focused on the family's experience at church after one of the children in the family was diagnosed with ASD.

The quantitative method used in this study allowed the researcher to obtain a wider picture of what types of programs are provided for church members in the study's geographical area (Creswell, 2009). The population of Christian churches in the area was determined and then stratified according to denomination to insure a variety of denominational perspectives. A random sample was drawn from this population to participate in a phone survey. The phone survey gathered demographic information and also included Likert-scale questionnaire on autism awareness.

### **Participants**

The qualitative and quantitative portions of this study used different sets of participants. The qualitative portion of the study drew on interviews from those associated with the case study—mother, siblings, and two church staff. The quantitative portion of the study surveyed churches drawn from a random, stratified sample in a mid-size metropolitan area.

#### **Qualitative Participants**

A qualitative approach was chosen to gain answers to the first four questions of this research study:

1. What types of support is a parent with a child on the autism spectrum looking for from their church?
2. What kinds of impact does a family's relationship with its church have on its ability to cope with the stress of having a child with ASD?

3. By what process does a church become aware of the need to support families who have children on the autism spectrum?
4. By what process does a church design programs to support these families?

In order to answer these research questions, data were required that provided historical information and a personal perspective. To generate these data, a case study format was chosen (Creswell, 2007). To select the case, first the researcher purposefully selected a congregation, Midtown Reformed Church (a pseudonym). This church has a ministry that has children on the autism spectrum attending. The family for the case study was selected purposefully from this congregation due the extreme nature of the child's diagnosis and behavior. In addition, this family had visited several churches in search of a religious community that would embrace their son, including a stretch of time where they did not attend church at all. Interviews were conducted with the mother, the siblings, the special needs coordinator of the church, and the Christian education director of the church.

### **Quantitative Participants**

A quantitative approach was chosen to answer the remaining five research questions regarding churches in the Christian tradition:

5. What characteristics of churches correlate with providing programs for families who have children on the autism spectrum?
6. What proportion of churches has a program specifically to support families of children on the autism spectrum?
7. How do ASD prevalence rates of attendance in churches compare with IDEA statistics?
8. What resources are churches providing for these families?
9. What is the degree of awareness of ASD among church staff?

To answer these questions, data were required that generated information from Christian churches in the chosen mid-size metropolitan area. Therefore, a demographic and Likert-scale questionnaire was given to church staff (pastor, administrative assistant or other knowledgeable church staff member) to provide demographic and attitudinal information. The random sample of churches was stratified according to church denomination to insure a variety of Christian denominational perspectives.

### **Instrumentation**

Both quantitative and qualitative measures were used to gather information for this study. The case study drew from a series of semi-structured interviews (Corbin & Strauss, 2007; Creswell, 2007). See Appendices F - H for the interview protocols. The church questionnaire consisted of a demographic information section and a Likert scale instrument (Creswell, 2007; Spector, 1992) that assessed respondents' awareness and attitudes towards ASD. See Appendix I for the questionnaire.

### **Qualitative Instrumentation**

Semi-structured interviews were carried out with the mother, siblings, special needs coordinator/Sunday school teacher, and the Christian education director associated with the child from the case study. The interviews were designed to provide a historical and personal perspective. Each person's experience relating to this child was recorded. In addition, the interviews were designed to understand the process of how a church provides relevant support for families with children who have been diagnosed with ASD. See Appendices F - H for interview format and protocol.

## **Quantitative Instrumentation**

A questionnaire was designed to gather data suitable for statistical comparison. The questionnaire had two parts. The first part was a demographic section to gather information such as attendance levels, denomination, number of children with special needs, programs offered, etc. The second part was a Likert-scale survey with 20 true statements about autism, intended to assess the person's awareness of autism. See Appendices I – J for questionnaire and survey.

A phone survey was done to gain information for the questionnaire and survey. A phone survey should have resulted in a higher number of completed surveys than mail-in surveys (Fowler, 2009). In addition, phone surveys cost less per return than mail-in surveys (Fowler, 2009). An online survey was considered, but the author did not assume that all churches could be contacted through email or that they had access to an Internet connection to complete the questionnaire. The results of an Internet survey might have skewed the data towards churches with more monetary resources (Dillman, Smyth, & Christian, 2009).

The mid-size metropolitan area chosen for the survey included the metro county and portions of four surrounding counties. A list of 1,100 churches was obtained from the Yellow Pages online under the key word "churches" and from a Google search of churches in the area. Churches were stratified according to denomination in order to provide a variety of Christian denominational perspectives (Baptist, Bible/Christian, Catholic, Church of Christ, Episcopal, Independent, Lutheran, Methodist, Nazarene, Pentecostal, Presbyterian, Seventh Day Adventist), and a random sample of 300 churches was chosen.



## **Procedures**

The study proceeded in two phases. The first phase was a series of qualitative interviews drawn from a bounded case study. The second phase was a survey of churches in the mid-size metropolitan area chosen for the study.

### **Qualitative Procedures**

Research questions 1 – 4 were answered through the case study, which was drawn from a purposive sample by locating a church with a ministry to families with children on the autism spectrum. The special needs coordinator of Midtown Reformed Church referred a family that was interested in participating in this research study that had a child with a severe form of autism. The child in the family has a diagnosis of ASD as determined by a psychiatrist as well as the public school system. In addition, the child had severe language impairment and sensory sensitivity. The mother, the siblings, the special needs coordinator/Sunday school teacher, and the Christian education director participated in a series of interviews to discuss their views of ASD, their perceptions of effective support, and the process by which the church developed its special needs program.

Interviews were conducted face-to-face and were audiotaped and then transcribed. The transcriptions and tapes were kept in a locked filing cabinet and are to be destroyed at the completion of this study. See Appendices F - H for the interview protocol.

### **Quantitative Procedures**

Research questions 5 – 9 were answered through a survey of Christian churches in the area chosen for study. Churches in the survey were drawn from the Yellow Pages online, key word: ‘Churches’ and from a Google search of “church” in the area. The list of 1,100 churches

was stratified according to denomination. A random sample of 300 was drawn to insure a proper sample size (Fowler, 2009).

Churches were contacted by phone. The nature of the questionnaire was explained and a request was made to speak with the pastor, Christian education director, administrative assistant, or other relevant staff who could authoritatively answer the questions. The phone interview took less than 10 minutes on average to complete. The first part of the interview was a demographic questionnaire and the second part was an ASD Awareness Assessment. A sample of the phone interview is found in Appendix I - J.

The demographic information from the questionnaire included denominational affiliation, size of the church, ethnicity/ies of the congregation, number of children attending church with special needs, and types of special needs represented (cerebral palsy, autism, Down syndrome, etc.). If the congregation had children with special needs in attendance, there was a checklist of the possible types of programs the church offered, such as counseling, financial assistance, respite care and other supportive assistance, religious education accommodations, social networking, and advocacy training. The interview ended with an opportunity for the respondent to make relevant comments to his/her experience with families with children on the autism spectrum. The results of the demographic section were compared with federal IDEA statistics from the local school system to give a benchmark of whether children with ASD were proportionally represented in churches.

### **Verification of Results**

This study used procedures to validate the accuracy of the findings. The first procedure was triangulation of data (Creswell, 2007). Multiple interviews (a total of six) were conducted (Creswell, 2007). Second, the researcher employed member checking (Creswell, 2007) as a part

of an ongoing conversation with the interviewees to ensure their intended meaning and perspective had been recorded. Third, this study was subjected to peer examination (Creswell, 2007) by the dissertation committee, that consisted of experts in the fields of qualitative and quantitative analysis, religious education, and autism. Finally, the researcher clarified her own personal biases for conducting this study (Creswell, 2007). This clarification can be read under the section, “Reflexivity Statement.”

Regarding study generalizability, qualitative studies long have discussed whether or not a non-randomly chosen sample can represent a larger portion of the population (Ritchie & Lewis, 2003). Qualitative results are not generalizable in the same way as quantitative results because they are not based on statistical methods. Instead they provide a “‘map’ of the range of views, experiences, outcomes or other phenomena under study and the factors and circumstances that shape and influence them, that can be inferred to the researched population” (Ritchie & Lewis, 2003, p. 269). Maxwell (2005) states that qualitative results can have “face generalizability” where there is no reason not to believe results apply more generally. Maxwell goes on to explain that when qualitative results show similarity to other situations and there is a universality of the phenomenon, then: “All of these characteristics can provide credibility to generalizations from qualitative studies, but none permits the kinds of precise extrapolation of results to defined populations that probability sampling allows” (p. 116).

The quantitative data from this study was generated by selecting a stratified random sample of Christian churches in the metro area. This method was intended to guard against threats to the internal validity of the findings. However, external validity could be threatened by church staff giving false answers to the test instruments, in order to give a more positive impression of the congregation than actually exists. The demographic questions and Likert scale

questionnaire would have good face validity, as these instruments ask directly for information specific to the study (Colton & Covert, 2007).

### **Reflexivity Statement**

As a part of the process of verifying qualitative research, a researcher must list biases and reasons for undertaking a study (Creswell, 2007). I am an Ed.D. student at the University of Tennessee at Chattanooga's Learning and Leadership program. I am a licensed professional counselor who has worked with families for over 20 years, many of whom have had children with special needs. In addition, I am the daughter of a minister and have a master's degree from a theological seminary. I have designed and taught a course at the seminary on ministry to families with children with special needs. Through my counseling and seminary experience, I became interested in the role of churches as institutions of community support for families in crises. This research study flows out of my observations that families with children who have a diagnosis of ASD were often isolated from their communities of faith. Through this research I sought to uncover what churches are doing wrong and what they are doing right in regard to families in their congregations who have children on the autism spectrum. I seek to begin a conversation among clergy and church members and raise awareness of these issues.

### **Qualitative Data Analysis**

Data for research questions 1 – 4 were gathered using face-to-face interviews. Results were interpreted according to content analysis techniques. These techniques emphasize the participants' points of view and allow the researcher to sort and make sense of unstructured information (Creswell, 2007). A constant comparative approach to content analysis is useful for case study data (Corbin & Strauss, 2007; Creswell, 2009). Therefore, data were carefully

analyzed for themes using a constant comparison approach to content analysis. These themes were coded and sorted into categories to see what patterns of information emerged from the data (Corbin & Strauss, 2007; Creswell, 2007, 2009). The project as a whole was submitted to three experts in the following fields: qualitative and quantitative data analysis, religious education, and autism spectrum disorder. This analysis provided rich, thick descriptions that reflected the perspective and experiences of those interviewed for this study.

### **Quantitative Data Analysis**

Data for research questions 5 – 9 were gathered using a quantitative survey. The data were non-parametric, nominal and ordinal, and were analyzed using SPSS to generate frequency distributions and to perform chi-square analyses. Chi-square tests are useful in the analysis of nominal, non-parametric data. Therefore, chi-square tests were used in the analysis of these study results to see if any significant differences between demographic variables could be determined between the observed frequencies and the expected frequencies presented in crosstabulation tables (Hinkle, 2003; Vogt, 1999).

In question 5 (characteristics of churches correlated with ASD programs) demographic information from the questionnaire was analyzed in the following manner. Some of the variables, (denomination, congregational size, number of full-time church staff, zip code as a socioeconomic measure) were recoded into groups for clearer comparisons. Chi-square tests were used to compare churches according to denominational category, congregational size (small, medium, large, and mega), number of full-time church staff groupings, and zip code categories with whether or not a church had special needs/ASD programs.

Question 6 (proportion of churches that have an ASD program) was analyzed using frequency distributions to determine what proportion of churches in the metro area provided an

ASD program. Question 7 (prevalence rates) data were compared with the metro school's IDEA statistics to determine if prevalence rates of church attendance for children with ASD were comparable to attendance in the local school system. Question 8 (what resources churches provide) was analyzed using a frequency table to determine the variation and rate of programs that churches provide. Question 9 (awareness of ASD) scores from the Autism Awareness Survey were summed and then divided according to a median split. Then chi-square comparisons were used (Hinkle, 2003; Sheskin, 2003) to determine if there were significant differences between high/low scores in the survey with variables from the demographic data. In addition, responses from the last question of the survey ("Do you have any personal reflections about ministry to children with special needs that you would like to add?") were divided into themes and coded, and then frequency tables were run to display the results.

### **Summary of Study Methodology**

To answer all nine research questions, this mixed methods study used a combination of qualitative and quantitative procedures. Qualitatively, the study obtained interviews for a case study of one family and the church where they attend. Quantitatively, the study used a phone survey to obtain demographic information and the level of awareness of autism from a stratified random sample of churches in the mid-size metropolitan area. Qualitative data were subjected to content analysis using constant comparative techniques. Quantitative data were analyzed using frequency distributions and chi-square tests generated by SPSS.

## **CHAPTER 4**

### **QUALITATIVE RESULTS**

The central question of this study is, “What types of support do churches provide when a member is diagnosed with Autism Spectrum Disorder (ASD) and what is the impact of this support on the family?” This was a mixed methods study, consisting of two parts. Questions 1 – 4 were answered through qualitative data collection and questions 5 – 9 were answered through quantitative data collection. In order to answer the first four questions of this project a case study was chosen to reveal one family’s experience finding a church to attend with their son, who has ASD. Four interviews were obtained from this family—the mother and three siblings. Two key members of the church staff were also interviewed in order to reveal the process by which the church became aware that families who had children on the autism spectrum needed special support and how a program was designed to provide that support. Results of these data are presented in this chapter.

#### **Findings on Research Questions 1 – 4 from Qualitative Data Analysis**

In order to understand how a church has an impact on the ecology of a family with a child diagnosed on the autism spectrum, the following questions guided interviews with the family and with church staff. Results of these questions are reported in this section:

1. What types of support is a parent with a child on the autism spectrum looking for from their church?

2. What kinds of impact does a family's relationship with its church have on its ability to cope with the stress of having a child with ASD?

In addition, questions were asked that reveal the process by which churches become aware of the needs of families with special needs and how they design programs:

3. By what process does a church become aware of the need to support families who have children on the autism spectrum?
4. By what process does a church design programs to support these families?

### **Research Questions 1 – 2 Results: Impact of Church on Family and Family's Perceived Needs**

This section addressed the results of the interviews from the family. Information was obtained on how the child in the family who is on the autism spectrum was diagnosed along with a description of his behaviors. The mother and three siblings consented to share their perspectives on how the church has provided support for them. All names given in this summary are pseudonyms.

**Family characteristics.** The Smith family chosen for the case study is a middle-class Caucasian family. At the time of the interview, they lived in the suburbs in a part of the metro area with the highest property values. At the time of the interview, the couple, Trisha and Sam, were married 20 years and had four children: David (17), Jacob (15), Sarah (13), and Sam Jr. (8). Jacob, the second born son, was diagnosed with ASD in the late 1990s when he was around the age of three.

At the time of diagnosis, the family lived in a mid-size city in the Southwestern part of the United States. Trisha had three children under the age of five. The family was comfortably



connected in their community with friends and family. Most of their relationships were maintained through the church where they regularly attended. Trisha explained the behaviors that led her to pursue a diagnosis for Jacob:

Jacob stopped turning his head to noises probably almost before two years, and I first noticed it with the vacuum cleaner, that he didn't have any response when I turned it on. So we thought he was deaf, and we took him to see [name of doctors] in [city] and did a lot of testing for hearing tests. And that's when they gave us the diagnosis of autism. And since he was so young the autism wasn't as obvious except for in the lining up of toys and running up and down the wainscoting of the wall and keeping that close to his eyes and those things.

As time progressed, Jacob showed impairment in social interactions: limited eye contact, difficulty making friends, difficulty understanding common social rules. He also showed impairment in communication: at times parroting back words or phrases, difficulty understanding other people's body language, gestures and facial expressions, and limited creative play. He displayed hand and finger-flapping, "meltdown" tantrums when his routine was changed and had obsessive interests. Jacob also had sensory issues that contributed to tantrums: bright lights were painful to his eyes and loud sounds were painful to his ears. He also disliked being in a large, crowded room.

However, his mother explained that he was still quite relational.

Jacob is very connected and very loving. Is he autistic? Definitely. I mean as far as being stuck on things and, from an early age just lining everything up in perfection. Nowadays he just repeats the same movies over and over and over, and he has to put the same sign up every day and that stuff. But is he a child that can't be hugged or loved or doesn't have bonds? Absolutely not.

Even though he and the family have felt an emotional connection with each other, Trisha reported that Jacob does not enjoy touch.

When he gives us a hug he kind of backs up to us and looks at us funny like, 'Okay I'll let you hug me.' I'll hold his hand in the car. He's 15; he looks like a grown man. But I just care for him so much that every once in a while I'll grab his hand because I want to. And he kind of holds it for a second and then let's go as if it's something really gross. So,

you know, he's still disgusted by touch and hugging, but he knows how to love. He loves very much.

When Jacob was around the age of five, the family moved from their close-knit community to a large metropolitan area about an hour away, still in the southwestern part of the United States. In doing so, they lost the ability to experience the close relationships of friends and family on a regular basis. At this time, they stopped attending church and were not able to replace the relationships they had lost.

About four years later, when Jacob was nine, the family moved to the mid-size metropolitan area in the south chosen for this study. Soon after this transition, Trisha decided to give church attendance another try. At the time of the interview, Jacob was 15 years old and the family had attended Community Baptist Church for around three years before transitioning to Midtown Reformed Church, where they had attended for about two years.

**Results on mother's perceived support needs.** Trisha was a petite, soft-spoken woman with a ready smile. She was willing to share her open and honest feelings with the interviewer, even though it was painful to discuss Jacob's autism. Trisha's needs were expressed as feelings and perceptions about the situation with her son's diagnosis of ASD, as well as direct reports of what she has needed from the church. The needs of the family changed as the family grew and developed. Therefore, the results of this interview were divided into three sections: needs at first, current needs, and anticipated future needs.

*Needs at first: Need for a diagnosis.* A theme that emerged from the parent interview early on was the need for a diagnosis to explain Jacob's aberrant behavior.

Looking back, I'm surprised that I even felt this way, but it was almost like there was a relief and excitement like, 'We've got an answer now; let's fix this.' It wasn't as

devastating as it probably should have been because we didn't know what we were getting into. It was kind of just we weren't in the unknown anymore.

***Needs at first: Financial needs.*** Another theme that emerged was the financial burden that came with Jacob's diagnosis. The treatment of choice for children on the autism spectrum was Applied Behavioral Analysis (ABA). ABA was an intensive, 40-hour-a-week program that was expensive to implement. Trisha came up with a creative strategy to find the funds to pay for Jacob's therapy.

When we did the 40-hour-a-week program, we were living month to month. We were just a young struggling couple. And I said, 'I'm going to raise the money.' So I sent out a flyer. I still have a copy of it, of him. It was a real beautiful picture, and it told about this ABA program and that it had helped so many kids, and I'm going to try it for two years, and could you commit to a certain amount each month. And so many people did and stuck with it. And then I think it kind of trailed off towards the end. You know, people wanted to see magic happen. And I mean, he did learn so many things. And I would send a letter every month trying to update what's going on. For that, I raised the money.

All the available money they had went towards Jacob's treatment and the care of their two other children. This financial burden made it difficult to afford babysitters so she and her husband could spend time as a couple. Trisha said, "We were a young family back then. Things are different now. So I never got babysitters ever. I think Jacob's first babysitter was probably in about sixth grade maybe; so just the respite alone [would have been too much to afford]." The important theme of 'respite' will be discussed later in the analysis of this interview.

***Needs at first: Need for guidance.*** Looking back, Trisha realized the importance of another parent to come along side her who could have provided some direction for her on what behaviors to expect and how to manage them.

I think [what I needed most when I first got the diagnosis] would be someone to come with knowledge who had walked it before because nobody else knew anything either, you know? 'When it gets like this, here's what to do.' And you know, I can be that for a lot of moms now, and I so didn't have that.

***Needs at first: Need for understanding from family and friends.*** Another theme that emerged from the interview was the need for support and understanding from those closest to her. Instead of support, however, most people in her family tended to minimize Jacob's diagnosis.

I think the first reaction was, 'Oh, he's going to be fine; he's just a little boy; he's just acting funny.' And that was actually very hurtful because I just needed everybody to take it seriously. And, no, you don't realize how hard this is and how different he is. But we'd go to family functions and it was almost like they were saying it's not there. Now that he's older they're like, 'Oh, okay.' They get it.

Trisha also felt that some blamed his behavior on her parenting. "But just when they're really little, sometimes it's almost looked as if it's a parenting problem."

***Current needs: Need to grieve.*** The theme of an ongoing sense of grief emerged throughout the interview. Trisha talked about how her grief has estranged her from her friends. She said, "When you're around people that are, say, grieving, you can support them for a while, but after a while it gets old. This didn't go away, and people just kind of, you know; there's only so much you can do. So they just kind of fell away." Even Trisha did not understand the depth of her grief at first. "I don't think I realized how hurt I was until he was a little bit older. I had lost a child that was okay and then wasn't okay; but I lived with him every day so it didn't go away." She felt like her grief compared to losing a child in death, yet with no final resolution. "It's almost like losing a child, the child you thought they were going to be."

Trisha also noted how isolated she felt in her grief. She said, "I needed someone to hurt with me. And it was almost like nobody was hurting with me." Trisha felt the invisible nature of Jacob's impairments contributed to her feelings of isolation. She said, "I think when someone pushes a child in a wheelchair and they are on a ventilator, that is a horrible thing, and you feel

for the mom. It's just autism is, they look so normal, and they walk with you, but nobody was hurting with me."

***Current needs: Need to surrender and move on with life.*** Trisha had pursued Jacob's treatment options with the idea if she worked long enough and hard enough, he would be "normal." She discussed the need to give up on the idea that her son would be cured.

When Jacob was between four and probably seven, his autism and his recovery was my life. We had a home program, and I've told you this, 40 hours a week. I mean it was everything, and I was a part of programs and newsletters, and I did everything we could do. And there did come a point where I had to say okay, enough. And so then a couple years after that, we had moved here, and I just said I wasn't going to make it my Bible, my everything, you know, the research and being a part of all this stuff. I just kind of let it go. And while I kind of would like to jump back in, I went to lunch with a lady very involved in that, and after I left lunch it was exhausting.

She found the world of autism treatment to be all-consuming and repetitive. Wading too deep into its details made her feel hopeless.

Sometimes it just gets disgusting after a while. You just want to be normal, be away from it all. It's the yuckiest part of my life. I mean, it's the one thing that I have that I wouldn't wish on anybody, and I just don't want to dive into that pool. I hate autism. And I feel like, you know what, I feel like I learned it all. I go to these things, and they'll be talking about the special diets and the wheat-free and casein-free, and I'm like, 'Oh I did that 10 years ago.' And hair samples and finding mercury, oh I did that. Chelation, oh I did that. There's not much new, you know? I've been there, done that, tried the ABA. I tried it all and nothing worked. Nothing cured him. But things help him, and we learned a lot. And maybe had I done it different or right, maybe he would even be better, but I can't live in curing him, so. It's just the path we're walking.

Trisha admitted that at times she felt guilty for not continuing to pursue Jacob's treatment full-time but in the end knew she had reached her limit. She had to move on with her life.

You know, there's guilt in being a quitter, and I just always said I just have to be done. I just have to be done. And then I have one of my friends who fights every cause, and she goes you know, you really should; and I just, I can't do it anymore. So there's guilt for not being able to fix it, you know?

***Current needs: Need for a “normal life.”*** The theme of missing a “normal life” was one of the strongest to emerge from the interview. Closely related was how Jacob’s “hard” behaviors were responsible for closing Trisha out of “normal life.” Trisha mentioned several times the importance of being a “normal” family. For her, one of the strongest indications of “normal” life was attending church as a family.

Well, to me [attending church] meant normal ‘cause I had grown up in the church. And okay, we’re going to be the family that doesn’t go to church? That wasn’t the family we’re supposed to be. And then I was sad for the other kids because then they don’t get to go to church either.

The family had attended church regularly before their son was diagnosed with autism. Trisha’s family and close relationships were all based out of the church. She said, “We weren’t on staff or anything, but we were like the regulars. Everybody knew my family. And there were home groups, those real intimate groups. And we were members, and our best friends were in there; so just solid members.”

As Jacob got older, his behaviors became more challenging (“hard”) and that led to the family dropping out of regular church attendance. Neither Trisha nor the church members knew what to do to handle Jacob’s increasingly severe tantrums.

[Jacob was] completely flailing on the floor and just kind of looked like a brat. And like I said, I wasn’t real sure what autism was going to be for us, so I wasn’t this big advocate. I would just take him out [of the service]. And when he was three or four he was just the hard kid. I think we just kind of gave up. We just stopped going. Nobody offered, but I never asked.

About this time, the family moved to a large metropolitan area about an hour away from their previous home. This move further estranged the Smiths from a church community. Trisha described the difficulty of finding a new church because Jacob’s behaviors were “so hard” and because she no longer had “the privilege of being normal.”

It had been so hard at the end with church that when we moved, we just didn't jump back in. I went a couple times, and it was so hard. My husband went once, and he came home and said, 'You know, I just don't see myself ever being a church member again.' I was just devastated. But one of us was in the hallway, and then the other one of us would be in the car with him. I just call it the privilege of being normal. People don't know how easy it is just to walk in and out of a service. And that's not the privilege everybody has when your kids can't be in Sunday school.

Trisha noted that part of the problem that kept her from pursuing another church was her reticence to ask others to help her. She didn't communicate her needs to others in the church.

I think a big barrier was I'm a very nervous person so I don't like to ask things of people, number one. Had I been a little more bold there may have been people to help. And we didn't go to people's houses because I was so afraid he would break something or how he would act because it had happened. I think just having the strength to be more bold, or people saying look I know this is hard but come anyway.

She was concerned about feeling misunderstood—that if she asked for help or talked about how hard her life was others might think she was only feeling sorry for herself. She was grieving the loss of a “normal” life and trying to come to grips with Jacob's “hard” behaviors.

I get worried that wanting someone praying for me or knowing my heart is hurting is—you don't ever want to say that person loves pity or anything like that. And I don't want to be that person either. Because, like I said in the beginning when we were talking, it never goes away, my prayer requests almost never change. It's just hard. Do I want pity from people around me? It's really not that. I think it's more of understand; understand that we're hurting; understand that it's just not easy and we'd like to be normal.

***Current needs: The need to attend church.*** After several years of not attending church the family moved again, this time to the area around where this study was conducted. This corresponded to the time frame when Trisha had begun to let go of a hope for Jacob's cure and had begun to move on with life, even though it would not be “normal.” After settling in to her new home, Trisha decided to see if there was a church that could accommodate Jacobs' behaviors. Because she was Baptist, she began systematically calling every Baptist church that she found in the phone book.

There was a long period of time, probably from age four or five till nine or 10, that we just didn't go [to church]. And I just wanted to try. And I called. I got the phone book out and I called every Baptist church...I called one, and they were like, 'Um I'm not sure, uh,' because I was saying do you have anything? 'Let me have someone call you back.' I just got off the phone and went, 'Okay, that's not going to work.' She obviously wasn't prepared, and so then I called one, and she said, 'We don't have anything, but I know of a church that does.' And that's when I got the Community Baptist Church name. And then there was a lady named Betsy Jones there who was the children's director, and I called her, and she was absolutely excited—excited about the kids and Jacob. She said they had a special needs program. When we actually jumped into it, they really didn't, but they were making a good attempt at it. Jacob, I think, was a shock to their little system they had going because she thought inclusion would be great. But he needs to be separate. He's just hard, especially then. Even now, he just, he doesn't enjoy the big group.

Because the church was flexible and found a way to provide care for Jacob, Trisha really enjoyed being a church-attender again. The church created an informal buddy system just for her son and this worked well for the first several months. "We had a great experience. When they figured that he couldn't be in [with the rest of the children with special needs], they found two volunteers with him while we would go to Sunday school."

The two volunteers formed a relationship with the family and went the extra mile to show Jacob that he was loved.

And they were just precious girls. They just were. The second time we went, it was Valentine's Day. And they had baked cookies for him. They would think of little projects to do. For about a year, they started taking turns or doing it together. What's funny about these two girls, they were gorgeous, beautiful girls. They could have been anywhere being all about themselves, and they were with Jacob, the funniest kid in church.

This plan lasted about a year and a half until Jacob's volunteers left for college. The church did not have anyone in place that would regularly care for Jacob with the same connection to the family. Instead the church "had kind of a rotation of volunteers, people that would just want to do it one Sunday." Sometimes Trisha's family had to miss attending a service and that was discouraging to some of the volunteers. The family and volunteers were not seeing each other on a regular basis.



Trisha and her husband had also become involved in the special needs program by volunteering their time with other children. A few months after transitioning to the rotating schedule of volunteers for Jacob, Trisha and her husband were asked to become the directors of the special needs program at the Community Baptist Church. “They needed a new director. So my husband said let’s just do this. We kind of felt like we knew what we were doing because we lived it, and we really did do a good job.”

However, this eventually came to an end. After about two years as directors of the special needs program, Trisha and her husband resigned and left the church. There were several factors that caused them to make the decision to leave Community Baptist. They were feeling “burned out” after experiencing some conflict among the special needs parents over where the program should be held. Also, they had lost some of their main support relationships as their Sunday school class had disbanded. But the biggest reason for leaving was that their other children were not happy at the church. Trisha explained:

When we left it wasn’t 100% because of being burned out. Our Sunday school class no longer existed. Our oldest son was miserable and fighting us going to the church. I chose the church because they took Jacob, but I didn’t choose the church that was probably best for our family because it was on the other side of town; not a single school friend from the Midtown area was all the way at the Community Baptist Church. As the kids got older they were kind of a group. You know, like we go to this high school or we go to that high school. And my oldest son ended up being on the outside of that, and then he didn’t want to go to church anymore. So then when they started to go to school here [at Midtown Reformed Church Academy] and the church was here, and their friends went here, then they wanted to be here, and their connection was here. Thankfully, so was Aimee [the special needs coordinator], and she had a program here.

Trisha discussed the transition to Midtown Reformed Church and the importance of Aimee, the special needs coordinator.

Well, it was the same thing as at the Community Baptist Church. Aimee, [the special needs coordinator] just told me how she could try to include him. I kind of had this panic of ‘Oh no, he’s in middle school and so is my daughter. She would die if he walked into the middle school.’ So she just said, ‘Maybe we’ll try the older elementary,’ because he

was probably still seventh grade at the time. Well, he just, he hears the music, and he's not interested in any of that or the group. She caught on very quickly that he wanted to be out of that room. She really wanted to try it, and sometimes you just have to let people try.

Once again, although the church did not have anything in place to provide Sunday school for a child with severe sensory issues and challenging behaviors, they were flexible and created a program for Jacob. At this church, they provided a Sunday school room for him in the only available extra space at the time—the church Christian education office.

So he ended up in the little office where they rolled a TV in there. And he likes the Veggie Tales videos and stuff like that. You just know when people get it and when they don't, when they can handle it. And she just, it was so obvious she was so okay with his quirkiness and his autism.

Most importantly Aimee communicated love and acceptance to Trisha, which made her feel comfortable bringing Jacob to church. For Trisha, her relationship with Aimee and Aimee's organizational efforts made all the difference. The family became regular church-attenders when otherwise they may have dropped out of church again.

Aimee is one of those people that she doesn't let it just fall by the wayside. She is on top of everything. She just has people lined up for him, and there was just no way to stop the ball rolling. I mean, I could have told her we don't want to come here, but she sure didn't make it easy. So she had people, and there's some Sundays we are like, you know, we could really use a break, but Jacob's counting on going and Aimee's got someone lined up so we better go. And we're always happy we did. It's so available now, you know? So, we are part of a church.

***Current needs: The need for intimate church relationships.*** While thankful to have a place to attend church and a place for her children to experience important social and spiritual relationships, Trisha did not feel personally like she had found a church home. Her family only attended for the Sunday school hour. She explained her feelings of detachment from the church even though she continued to attend. First of all, she found it difficult to break into long-standing social relationships in the congregation.

I don't know a lot of people in our Sunday school class. And I think, sometimes they talk about, 'Our city is like a big small town.' It has a very small town feel; people have their friends and have their um—it's very hard to break into that. So we've been coming here, and we're still very new.

She also experienced most of the social interaction at church as superficial. She felt there was an unspoken social rule to keep your problems to yourself.

I think [we've been attending here] maybe two years. And a lot of people don't empty themselves at this church; and everybody looks really pretty and drives really pretty cars; and our Sunday school class is not, 'Let me open up and get to know you.' So yeah, most people don't even know anything about our family unless it's gossip here and gossip there. It's not close. There may be a few people that are close or that have been here forever, but it's not that way for me.

However, Trisha explained that attending church had a benefit for her. She was able to hear preaching and experience worship.

[Our Sunday school class] is very much like a church service. So I think that's why we feel like we don't need to go to church afterwards. I mean it's in the chapel, and there's a speaker and it's very much like a church service. It's not like a small group. The guy who does the teaching has a great message every week. It's not dry and boring. So I love that. I mean you walk away feeling fed, not fed in that community kind of feeling or the small group. They may have that at this church, but I don't know.

What was most important to Trisha at the time of the interview was that her children were able to experience church. Trisha was glad her children had important relationships with peers and with the youth leaders. "So they come and they see their friends, and there's good leadership also."

All of her children enjoyed attending and there were no arguments or disagreements about going.

I know my other kids get to go to church. And that, for me, is a big deal. I don't have to have the best situation, and I don't even think we'd be at this church if it wasn't for my other kids. But right in this season they need to be where they want to go or it's going to be a fight every Sunday morning because we've got 17, 15, 13 and 8. And if they don't want to go it is miserable.

She felt that this is where they were to attend for now, but did not rule out a change at some point in the future to a church with a less formal style of worship and where she might be able to experience more intimate friendships.

I don't know that we'll always be at this church, and that's why we've been visitors for two years. Even if we joined we'd get a tuition break, but that's no reason to join a church. It's a season of our life; this is where the kids need to be, and Jacob has a place to be. And maybe we'll one day go, 'Oh, I guess we are Presbyterian.' But we're Baptist; but this is where we're supposed to be...I've visited other churches, and I feel more drawn to Grace Chapel where there's more, it's just a different style. [I'd like a church where] I know you well enough to say it's been a horrible week. I don't have that at this church, but that's okay because this is where we're supposed to be right now.

***Current needs: Need for spiritual comfort.*** Trisha talked about the spiritual struggle she went through, wondering why her son had such a severe form of autism. At first, she thought maybe it was her fault. "I've thought, and this is probably stupid, is this punishment for something? Who knows?" She spent time in prayer wrestling with God over her son's condition. She explained, "I think he was probably in second grade when I just one day, I was just kind of yelling at God, 'Why would you? He's supposed to be your son, too.' You know, 'You're his Father; why would you do this? He has no life.'"

However, it was in the community of the church that she found some sense of resolution to her struggle.

I kind of had an 'aha' moment in a Sunday school class one time. This was at the Community Baptist Church. That was the first time we found a special needs [class], someone who would stay with Jacob. And this Sunday school teacher said sometimes your answers are not about now. And he said it may be about something in heaven, something eternal. And that was the best thing I could hold onto because I really wanted an answer. Why didn't he get a normal life? So that was my relief. That was my relief.

This realization changed her focus and helped her move past the driving need to find a cure for her son. In doing so, she was able to accept the small victories that she has seen.

I had to give up all my prayer demanding an answer and a cure and just say it's got to be not about now. But I do get to see the little things, and I wanted to see the big one, and I don't think I'm going to get that answer. I had to just resolve that that was my answer. It's not about now; it's about something that I'm not going to get an answer for. And I'll be happy if I get one, but I never said I don't think you're there God, or I don't think you're in control. I did say why, why; this is so mean. But I still know God is God, even

without the big answers and my answers. And I have to know that this is about something bigger, and I'm not getting the answer.

When asked if she felt spiritually supported by her current church, at first Trisha had difficulty conceptualizing 'spiritual support.' She responded:

I don't even know what I would expect spiritually, how someone could support me. I don't...I wouldn't even know what that looked like. We are just so independent. You know, I don't know. You'd have to ask a more detailed question because I'm drawing a blank.

Later she understood spiritual support in terms of a close, caring relationships in a religious setting. She replied that she felt supported by the special needs coordinator, but not by the larger congregation.

I feel supported by Aimee because of her heart running this program. But no, I don't think anybody even really...But we're not members. And it's not because anybody's been mean or ugly or anything. This church has deep roots, you know? It's a big church, and there are people that have been here for years. So it's not because of the heart of the church. It just is what it is. Also, I don't think anybody [at the Community Baptist Church] took it on as their mission to make sure we were okay or would even notice if we didn't come back for a month or so.

Trisha felt that perhaps one must live in a small town to experience the kind of close relationships she had experienced before her son's diagnosis. "I think because we don't live in a town of 400 sometimes people just don't know each other or don't even know where they live, but smile at each other. It's kind of like a false friendship." Trisha said the last time she felt supported by a church was before Jacob's diagnosis. That was the last time she had "the freedom to be normal and be a part of everything."

When asked if it is possible to be supported by a church if you are not "normal," she responded, "You know, sometimes a lot of church is not about being blessed. It's about being a blessing, and that's how you're involved and appreciated, and the person who constantly has to sit back and be blessed..." When further pressed on if her role in a church was to receive

blessing instead of be a blessing, Trisha responded by saying that level of support would feel like she was part of a family. It would include shouldering part of the burden of caring for Jacob. It would also include others expressing empathy and understanding for how having a child on the autism spectrum affected her family's functioning.

If I was receiving it how would it look to me? If somebody cared about us like my family does, like my father does, and said, 'Hey can we come take him for a night,' or just even realize, 'Oh, y'all can't even go to a basketball game, can you, because the noise, there's no way.' So I think from a church, having Sunday school is great, great, great. And then if you want to take it a step further, 'Gosh, can I come over and y'all go do something, and y'all pick that.'

***Current Needs: Need for respite.*** The main theme that emerged from Trisha's interview was the need for respite. For Trisha, respite meant having the ability to experience moments of "normal life." In addition to the Sunday morning respite at church, she discussed three other sources of respite: the monthly program run by the county rec center, her parents, and sitters who spend time with Jacob during the summer and afterschool during the school year. Trisha's foremost source of respite was her financial ability to pay for sitters since she and her husband had increased their monthly income. In this way, she did not feel like she was impinging on anyone else's patience or charity.

First she discussed the importance of the community program.

I take him to a respite now one Saturday a month, if I can get him in at the rec center. I have to stand in line early in the morning to get him in. That day off is so wonderful just because I don't have to worry... The respite that he goes to that is such a blessing; it's from ten in the morning till three in the afternoon, and they play the Wii and they take them swimming so I know he's getting to have fun that he doesn't usually get to have. I have never experienced a respite care like they give. We pay \$20, which for a whole day I'd pay \$100. I don't want to tell them that, but I really would. And Jacob knows it's coming, and he puts it on his calendar. That's why I have to be in line at registration 'cause then I'd have to deal with him crying. It's the best thing I've experienced as far as care because there's a lot of time and they do a lot with them. So the rec center is the best one, but it is so limited. There are 20 kids that get in and 60 that try every month. And it's

only one Saturday a month. So while it's wonderful, they only do it about 8 times a year, and they don't have it in the summer.

While Midtown Reformed Church also had a once a month Saturday respite program, their program was only for a couple of hours in the morning. By the time Trisha drove Jacob to the program and got back home, it was almost time to go and pick him up again. Therefore, Jacob did not attend the church's Saturday respite program.

Secondly, Trisha relied heavily on her parents for further respite.

Our biggest support is my parents. They actually moved here after we moved here, purposely, to help us out. They love our family. So anyway, our biggest support is them. And how they show that is they take him every Friday night. So during football season we get to go to the football games as a family or if my other kids are out doing their stuff my husband and I can go on a date. But we usually just love staying home and being in a normal house because you cannot imagine how different it is to have time without Jacob...what it is to not hear the rewinding [of videos] all the time. And Saturday mornings everything just seems more picked up because he's a mess. We probably get more done in that 24 hours time than we do in a three day time. It's just, it's different. We can watch a whole movie together without getting up six times and without competing for the volume with him. So that's one of the neatest things...So it's just that third parent that's willing to actually be a parent because you can only ask so much of babysitters. But they really are the third parent.

Finally, she discussed how her ability to pay for respite care during the summer and after school gave her the time to do other things. She said, "I've replaced [the support we used to get from family and friends] with us reaching a financial place of being able to pay people. A year and a half ago, I thought, 'I can't be home all summer with these kids. I need a couple days.' I actually wanted to work." Her connection with the church helped her find excellent sitters for her son.

I approached Aimee, and I gave her this write-up that I was looking for somebody. I said, 'Since you're doing this you might know someone.' And she sent me an email saying would you consider my son, Andrew, who had just graduated? He was going to be home for the summer. And I just thought well, she has just a heart, you know, and he's 18 years old, and it's probably trickled down. You know, the apple doesn't fall far from the tree.

So he turned out to be just amazing. He would take Jacob on walks and take him to the park and make him throw rocks in the water for hours and just did boy stuff with him. And then he went off to college. And this is just kind of such a God thing, a senior boy actually approached me. And he said, 'I was Andrew's friend this summer, and I would really like to have his job.' He wanted a shot at it, too. And part of it is I pay well because I would quit if I got paid minimum wage because it's, you know, he can be embarrassing in public. He can be challenging. These are just good boys that, they stick with him. And it's not easy.

Trisha explained how extended periods of respite from Jacob's "hard" behaviors changed her life.

How does it affect me? I feel so free. I used to feel so stuck in my house. I was stuck because it was too hard. And then I don't resent Jacob so much because I've had this bit of blessing or break or not so tied down. It really is difficult when they get older because when they're little, another mom with little kids will say just bring him over and let them roam around. Roaming around at two or four looks a lot different than at 15 or 16 when they're a bull in a china shop, you know? So just the freedom to not be nervous all the time and, you know? Let me get this over with; let's go shopping; I'm going to drag him in, and it's going to be really hard.

She was no longer 'stuck' with constantly having to manage the 'hard' aspects of Jacob's autism. She was able to experience moments of "normal life" again and had the ability to spend time with her other children.

[Before the respite] he would get off the bus at 2:30 at my house, and I'd have to put him in the car. And we'd go wait [for my other children to get out of school]. Now, I have someone get him off the bus, and I can come be a mom and walk in the hall and get my kid. I'm not sitting in the car just going, 'Oh, I wish I could walk in with the other moms; I'm stuck because I can't take Jacob in 'cause he'll go in a classroom or he'll act crazy,' you know? It's just a terrible feeling of being stuck everywhere you go.

***Anticipated future needs: Need for care as Jacob ages.*** Trisha noted that not many people enjoy caring for those on the severe end of the autism spectrum.

I think because autistic kids generally are beautiful kids, unlike some disabilities which definitely identify them, there's not as much compassion from people because they don't see the disability. It's something you have to see in their behavior, not in their face. And I can see even just almost the disgust [people feel towards children with autism]. Like there's some people that say, 'Oh, we love the Down syndrome ones,' or 'We love the wheelchair ones,' and then autism kids are the behavioral kids, the hard kids, the ones



that hit and fight and nobody wants. Nobody wants to do anything with them, especially when they're younger and harder. And it takes a completely compassionate person who doesn't take anything personally and is 100% just laying down that moment for that kid because it's not fun. It's the ugliest disorder when you're mean and hateful and don't even know you're being that way.

She expressed worry over this and discussed how she looked ahead to the future and made plans for her other children to provide care for Jacob after she and her husband are no longer able to provide care.

My older kids, the 17-year-old and 13-year-old that are on either side of him know that they're going to have to help some day. I've told them, 'I'm glad Jacob has you guys and he's not an only child,' because there are so many autistic kids now. What are people going to do? It's kind of like the elderly; good families take care of them. And hopefully, we can be that for Jacob.

In summary, Trisha's needs changed over time. At first she needed a clear diagnosis, a plan of action and the finances to pay for treatment. She also needed guidance from someone who had experienced what it was like to raise a child on the autism spectrum and she longed for a greater degree of understanding from friends and family on the seriousness of her son's diagnosis.

Her needs at the time of the interview were to grieve in an atmosphere of understanding that her sorrow is ongoing. She also expressed the need to give up on finding a cure for Jacob and to move on with life. She longed to return to the "privilege of being normal," and wished that Jacob's behaviors were not so "hard." A central component to a "normal life" for her was belonging to a church. The key to recovering as much normal life as possible was respite. Respite at church during the Sunday school hour allowed her access to this important part of "normal" life. This also gave her children the ability to participate in "normal" life and form important spiritual and social relationships at church. The county rec center was another importance source of respite and provided approximately one morning a month free from her

son's demanding behavior. Her parents were another important source of respite, particularly on weekends. But mainly it was her financial position that gave her the ability to obtain a higher degree of respite without relying on the volunteered time of others. This bought her snapshot moments of "normal" life: just being a mom picking up kids from school, shopping, attending other children's sport activities, getting away from the constant pressure of her son's behaviors and the 'ugliness' of autism. All of these sources of respite combined to buffer her stress—she felt less tied down, less nervousness, and had more pleasant interactions with Jacob when she was with him.

**Results on older brother's perceived support needs.** David was Trisha's 17-year-old son and Jacob's older brother. An excellent student and an athlete, he presented himself as a confident young man with a great deal of compassion. His earliest memory of Jacob was of Jacob in kindergarten, "rolling around on the floor, just screaming. That happened a lot in elementary school." David admitted this was difficult for him to adapt to when he was younger, especially when he was in elementary school. He said, "Early childhood through like fifth grade probably would be that period where I didn't really understand any of that." Even now, Jacob is prone to tantrums when his routine is changed and David has had to be flexible to accommodate his brother's behavior.

With Jacob it's very sporadic, our schedule, because we could be doing one thing at one time and, say Jacob flips out or he has a temper tantrum. Well, someone's got to be there by his side to calm him down. That's usually my dad. And say I was planning on running with my dad or something like that, that would definitely interfere. Or say I was planning on going out to eat with my dad; that probably wouldn't happen as a result of Jacob.

Because of this David felt he has developed a greater sense of patience. When asked how having a sibling with autism has shaped his life, David responded:

Well, it's definitely made me more patient; definitely made me more understanding of people. I think I can put up with a lot more stress than a lot of people can—like a lot more; I guess chaos is a better term, 'cause there's just so much that comes with autism, especially with Jacob. I actually think I understand autism in general more than others. I think that's natural. Like if you have an autistic brother, you kind of learn stuff through the process.

David discussed the difficulties of communicating with his brother. He said, "I think deep conversation would be very difficult with him just because of his level of communication."

However, David expressed his view that Jacob was able to comprehend more than people realize.

But I think deep down he does know what's going on just because you can see that in a lot of aspects. I've had people sitting next to me, and they'll look over at him, and they'll say, 'Well, does he understand what we're saying?' And Jacob will look over and give us the most human look ever. And my friends would just be like, 'Ooh, that's embarrassing.' And you know, he does know what's going on.

***David: Need for structure.*** When asked the ways his church supports his family, David responded that attending Sunday school brought some needed structure to the family.

I think [attending church] helps because I would say it's kind of a time of structure for us, which we don't get a whole lot. You know, my parents go one place. Sarah and I go another place. Sam, Jr. goes to his Sunday school class, and Jacob is in the special needs program. It's just a moment of structure, which is greatly appreciated in this house because again, we just don't get a lot of that.

David also mentioned how important structure is for Jacob.

Jacob loves that. He loves having structure. I mean Jacob sees things in black and white. He has to have consistency. He knows church is on Sunday. That's where he goes. He sees Miss Aimee, he gets his doughnuts, he rewinds Veggie Tales a certain amount of times, and then he's out of there. And that's his Sunday.

When asked how the church supports his whole family, David responded:

I would just say really good leadership. They're really organized, I would say. I mean that's what I see in the youth department. I don't see a whole lot otherwise because I only go to big church every now and then just because of time restrictions on Sundays. But yeah, the main thing is I would say they're really organized and structured and have great leadership.

**David: Need for friendship.** David had been able to attend church as a family at the Community Baptist Church, but did not have friends at the church because of the way the leader had divided up the youth.

Well, the main thing was the leader; he split the groups up by school. Whichever school you went to, you were in a certain group. And nobody from my school really went there, so I was in a group of like three people, and I didn't like either the other two. And the leader would always go and hang out with the kids at one particular school, really get to know them. There was really nothing else with any other school or any of the other kids. It was just kind of like that one group of kids that he focused on. I guess it's more bad leadership than actually the church itself.

David took the initiative for the family to try attending Midtown Reformed Church because he had friends there. He had transferred to the church's school and decided to try the church by himself at first. "I just knew a lot of people that went there so I decided to give it a try. And I liked it a lot better than Community Baptist Church."

**David: Need for respite.** David found out about the special needs program at Midtown Reformed Church and after his mother met the special needs coordinator, the Smith's attended church as a family. Without the Sunday morning respite program at the church, this would not have been possible. David described what the church offers Jacob.

The main thing is they offer him a place to go during church. While we're off in Sunday school or even if we go to big church, there's always a place for him to go. I feel that they've probably done the best job out of any special needs program I've seen, whether it be at school or church. They basically keep him in this decent-sized room. They've got two adults with him, two really patient adults. They have a lot for him to do. They bring him doughnuts, which might not be healthy, but he loves it. They keep a TV in there. They're really good to him. So that's basically what the church provides.

David enjoyed attending church with his whole family. "I really like it. I like being able to go to church with my family. I definitely think it's better as opposed to going by yourself. I mean that's part of the way I'm wired." David felt the church supported his family very well. When pressed for how the church could provide anything else, David responded:

Honestly I think they're doing a great job right now, but I think maybe, and this is a huge stretch, this would probably be asking them to go above and beyond, but maybe care for Jacob outside of church. But other than that they're really doing a great job there, I feel.

He explained more about the importance of respite for his family.

We get babysitters for Jacob during the summer 'cause we're all busy. And we used to be really kind of confined to the house because of Jacob, because someone had to be watching him at all times. But now we've got babysitters. I think maybe getting some people from the church to kind of be in that role. But again, that's kind of over and beyond. I mean I don't know.

David discussed how attending church reduces stress in his family.

Beforehand everything was kind of, I wouldn't say it was bad, but it was definitely more chaotic than it is now. And my parents were pretty stressed then. I'd almost say they were more stressed going to church [where they were in charge of Special Needs at Community Baptist] because they didn't go to church. I would say they're not nearly as stressed as they were before.

***David: Theology of ministry.*** David discussed how important it is for a church to have a special needs ministry. He first mentioned that parents would not be able to attend church if there were no special needs programs.

I think, like you said, people just can't find programs for their kids. They can't find stuff for their kids to do while they're at church. I know a lot of churches don't offer that, because we had to search pretty hard for a church that had a special needs program. The first one we bumped into was Community Baptist, and even there the special needs program was sketchy at best. I mean it wasn't even a real special needs program until my parents stepped in. But they still offered one, which was nice.

He also discussed his view of the theological reasons a church should minister to those with special needs.

I would say so long as [churches] use the Bible as a reference for their faith they're kind of obligated to because I mean there's a verse, it's Matthew 25, in the Bible that says what you have done for the least of these you have done for me. So if they are Christians, it's kind of obvious that kids with special needs, they're in that group. They're the least of these. I think any church that believes that verse and that uses it in sermons and that preaches that, I almost think they're obligated to have one.

In summary, David needed a church that supported him as an individual and as a family. His former church had provided for his brother, but not the siblings. David had not felt any connection to the leadership or to his age-mates. In contrast, he felt very connected to friends at Midtown Reformed Church. He expressed the importance of attending church as a family and how that provided a much-needed morning of structure. The respite program for the Sunday school hour was essential for the family; his brother was also welcomed and supported. David mentioned the possibility that a church might consider providing respite outside of the church as well. That would give a family freedom to participate in more activities and to reduce the stress of living with a child on the autism spectrum. Finally, David talked about his theology of ministry, that according to his understanding of the Bible, churches are obligated to provide a special needs program.

**Results on younger sister's perceived support needs.** Sarah is Trisha's only daughter and Jacob's thirteen-year-old younger sister. A lovely young woman involved in cheerleading and other athletic events, she presented herself as a bit shy and nervous, yet willing to talk about her brother. She discussed the positive effect Jacob had on her life, saying it had been good for her to see things through her brother's eyes, because, "He finds happiness in other things that we wouldn't."

It's hard to understand, but he can do things. He laughs about the most unique things. It just makes us smile, I guess, that he can understand and find happiness in these little things that we can't. It makes you pull out the good things and think more positive almost and just see the positive side.

However, she noted that his behavior is often challenging. She reported that "small noises get to him," and that he has "random outbursts" that are "hard to deal with." She said, "If we go to the store with him, he has to have something. And if we say no or something, he gets angry really

fast.” She has tried very hard to accommodate him to minimize his outbursts. One way to do this was to help her mother cook.

I love to cook. I know what Jacob likes to eat. Like if we’re all making a family meal or something, we’ve got to make a separate meal for Jacob. That’s a really small thing, but because he’s so picky. But I mean it’s worth it, making the right stuff because we don’t want him to get upset again.

Several perceived needs emerged as Sarah was interviewed: the need for friendship, respite, and spiritual education.

***Sarah: Need for friendship.*** The first church Sarah remembered attending was the Community Baptist Church. She said she was not happy there because she “didn’t have any friends there really.” During that time Sarah began attending Midtown Reformed Church Academy and had made several friends. Almost all of them were attending Midtown Reformed Church. She said she felt connected at this church because, “We know everyone and the leaders talk to us.”

***Sarah: Need for respite.*** Sarah perceived that access to church depended on having a Sunday school classroom for Jacob; otherwise she would not be able to attend regularly. She thought every church should have a special needs program. She explained, “It’s so hard. And when we’ve looked for churches, we have to find a place that could take care of Jacob too cause we want to go all together. We like don’t want to split up like two of us go this week, two of us go that week with Jacob.”

She noted that attending church, “gives us a break from each other almost.” And that it was important for the family to be able to rely on the church to have someone there for Sunday school; otherwise Jacob would not want to go to church and the family would have to divide up and someone stay behind with him. She said, “We used to [divide up] a lot, when we went to

Community Baptist, because sometimes people wouldn't be there. But now that we're at Midtown Reformed they're always there consistently so we don't have to." Because the family can rely on this respite, it has reduced the stress in the family.

[My parents] are happier because they look forward to church more. It was hard because they'd have to get everything together, and then maybe they can go over for 10 minutes to hear part of the sermon, but now they can go and know that someone trustful that we know is watching Jacob.

When asked what she likes best about her church, Sarah replied, "That it does offer a place for Jacob, that we can all go there, and that we know everyone."

***Sarah: Need for spiritual comfort.*** Sarah said her relationship with God is "pretty strong." She enjoyed attending her church and liked having time where she can "go focus on God." In addition to Sunday school, she said, "I go to my D group, which is like a little small group we get in at church every Wednesday. And then I love the camps...the worship part 'cause we can just, like no parents are there really. It's just all the rest of my friends and we can just really get to know God."

In summary, for Sarah, church attendance meant access to deeper friendships, an opportunity to do something together as a family, and the opportunity to worship and learn more about God. She was dependent upon the church providing a source of respite so that she could attend church with her family. The Sunday morning respite helped to reduce the family's stress by providing an opportunity for them to experience church together.

**Results on younger brother's perceived support needs.** Sam Jr. is Trisha's youngest child and Jacob's 8-year-old younger brother. He was a bit shy for the interview, but was pleased that someone was interested in his opinions. He said the best thing about Jacob was, "He kind of



makes funny faces sometimes and he repeats words from the old kind of cartoon movies 'cause he likes those. He watches videos. So he really likes it, and it's really funny 'cause he repeats it."

However, Sam noted that Jacob's behavior was sometimes difficult. Sam did not enjoy Jacob's tantrums. "Sometimes he gets angry because the computer doesn't work, because he really likes going on the computer, and he cries and it's difficult to get him better. And when someone's sad, he'll just like start crying. I don't like it very much. So it's very difficult."

***Sam, Jr.: Need for spiritual comfort.*** Sam Jr. had been struggling with Jacob's "differentness." He found it awkward to explain about Jacob's autism when others asked him about it. "Well, it kind of feels weird because lots of people don't really have autistic sons, and so people just ask me what autism means. And I have to tell lots of people. And it's not really fun telling people."

In Sunday school he learned, that despite outward differences, inside people are the same. He said, "And then in church I heard that no matter what, no one's different because of the outside, but the inside, you're not different; you're all the same. So I know my brother isn't different from people." When asked how church makes his life better, Sam responds: "That they tell me about God and that Jacob isn't different from us."

***Sam, Jr.: Need for structure.*** Sam expressed his need for his family to have a reliable routine for Sundays. First he discussed Jacob's routine:

Jacob really likes going to Miss Aimee. And he likes to be helpful to Miss Aimee. And he brings lots of videos in this blue bag that he really likes. Then he puts them into the TV. Then he watches them. And if Jacob doesn't get bad, Miss Aimee says he can get a cookie. Actually, he gets a doughnut. And he really likes it.

He then discussed his routine:

I go to church. And then the first thing we do is do a project. Sometimes we do a project; sometimes we act stuff out of the Bible. And then in the middle we always talk about the Bible. Then at the end we get these papers about the people that we're talking about in the middle.

***Sam, Jr.: Need for respite.*** Sam expressed that the church was a place of respite for his family on Sunday mornings. This respite reduced his parents' stress and arguments. "Well, it helps [mom and dad] get a break from Jacob so that can't get like argued."

In summary, for Sam Jr., church was a place where he could resolve some of his conflicted feelings about Jacob. He expressed the importance of the structure of the family's Sunday morning routine. For him, this morning of respite that the church provided on Sundays helped reduce his parents' stress levels.

### **Summary of Research Questions 1 – 2 Results**

What types of support did this family need from their church? Several needs were expressed in these interviews. Some were specific to the individual and some were shared by more than one family member. The need for respite was mentioned in all four interviews. The needs of friendship and structure were mentioned in three. The need for spiritual answers was mentioned in three. Trisha discussed the needs for guidance, to grieve, to surrender, and to experience "normal" life, which included church attendance. She needed a church that was aware of autism spectrum disorders and the kinds of issues she faced. She needed people in the congregation to understand her son's behaviors, and to understand that her grief was ongoing and would not resolve. She also talked about her future concerns of who will care for Jacob when he is older. See Figure 4.1 for a Venn diagram of the Smith family's perceived needs.

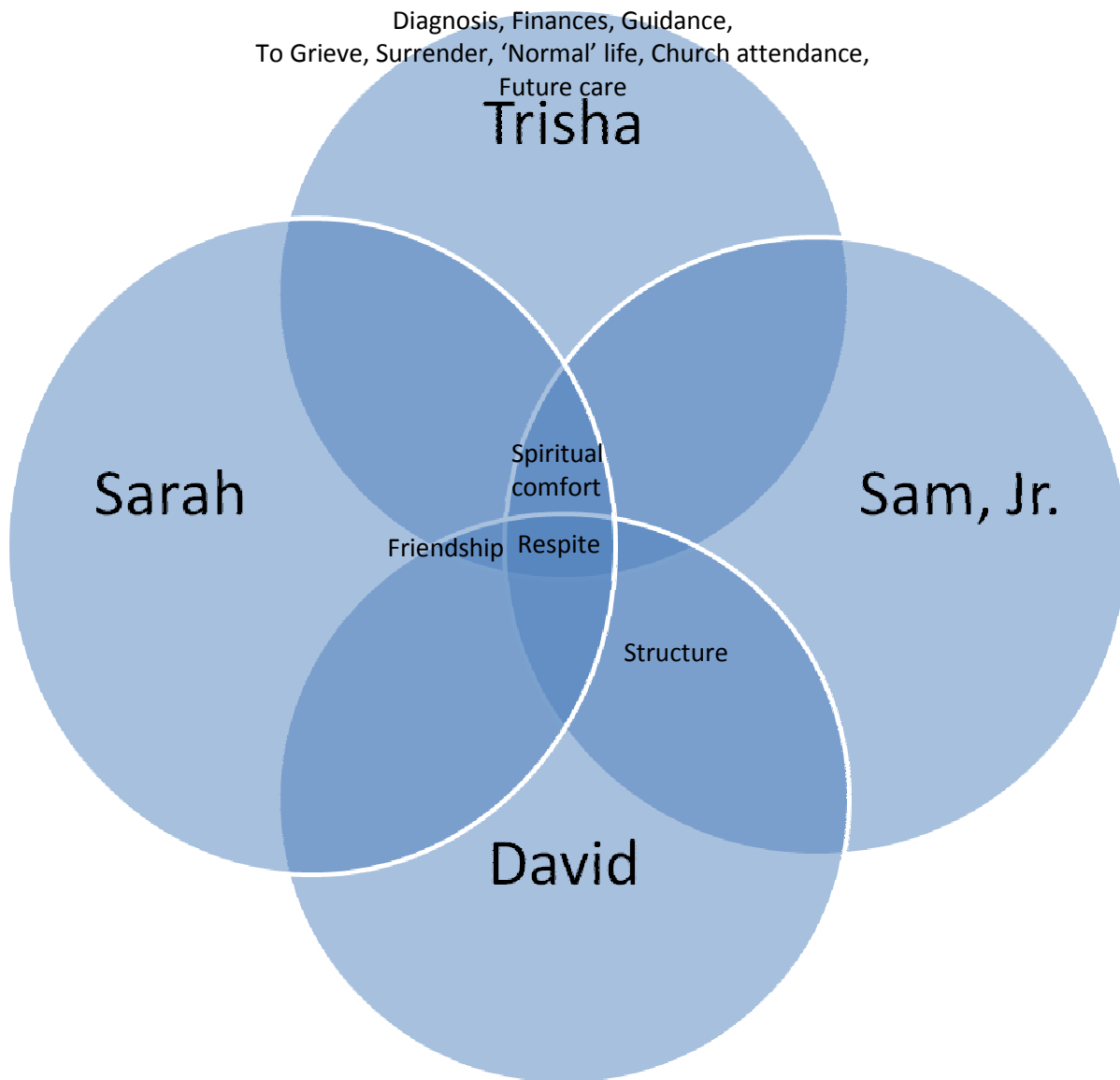


Figure 4.1 Venn diagram of the Smith family's perceived needs.

The main need this family expressed was the need for respite. Respite paved the way for the family to meet many other needs. The family needed the church to provide a Sunday morning program for Jacob so they could attend church as a family. They needed that program to be enjoyable for Jacob and for the adults who worked the program to be caring and trustworthy. Respite at the church provided a way for the family to do more than just attend Sunday school. It

provided structure for the family and an opportunity to form friendships, to worship God, and to receive spiritual answers.

What kind of impact does a family's relationship with its church have on its ability to cope with the stress of having a child with ASD? All four family members who were interviewed agreed that Jacob's behavior was difficult to deal with at times and that this caused stress; and they expressed that respite decreased the amount of stress in the home. When someone other than immediate family was providing care for Jacob, then the family was free to experience many other aspects of life that would otherwise be out of reach for them.

### **Research Questions 3 – 4 Results: How Churches Design Special Needs Programs**

Questions three and four sought to reveal the impact a church has on a family with a child on the autism spectrum. Question three asked by which process did a church become aware of the need to offer support to families with children on the autism spectrum. Question four asked how the church designed programs that would meet the families' needs. Two staff members from the Midtown Reformed Church where the Smith family attended were interviewed to find answers to these questions.

**Church characteristics and history of special needs program.** Midtown Reformed Church (a pseudonym) was located in an affluent area of the metro area and was affiliated with a mainline protestant denomination in the Reformed theological tradition. The congregation was comprised of 1,200-1,500 attendees. The church employed more than 20 full-time staff and several part-time staff and shared space with its academy that provided an education for children from pre-school through high school. Several ministry opportunities were offered to members who wished to volunteer their time to help others.

Midtown Reformed Church started their special needs ministry 18 years ago when a member of the church gave birth to a child with Down syndrome. Friends of the mother noticed that she was not attending church regularly anymore and offered to stay with the child in children's church while the mother attended worship. Slowly, other families with children who had special needs began to attend the church and eventually the ministry was formalized into a volunteer program called, *God's Love to You*.

At first, *God's Love to You* was only a buddy system for Sunday school and children's church. Different volunteers in the congregation were paired with a child with special needs as an aide to the Sunday morning teachers. Children in the program were mainstreamed into the regular church activities. Typically church members volunteered one or two Sundays a month; therefore, each child was assigned two to four buddies. For several years, the program was overseen by two volunteers, but grew to the point that about four years ago the CE director asked for the church to pay for someone to manage the program on a part-time basis. It was at this time that Aimee Parrish was hired and the church had its first child on the autism spectrum begin attending with his family.

About three years ago, some of the parents who had children in *God's Love to You* asked the special needs coordinator if the church could provide an occasional respite outside of Sunday morning. Aimee researched other churches to see what programs were offered and developed a respite program on a smaller scale for the Midtown Reformed Church. This program, called, *Special Saturdays*, provided two hours of respite one Saturday morning each month at the church. Parents and siblings were welcome to stay and spend the morning's activities with their child who has special needs, or they had the morning to do other things.

From this program, two years ago *God's Love to You* expanded to summer activities. An occasional activity such as a sock hop or a family movie night was offered. That summer, the church also provided a Vacation Bible School (VBS) for children with special needs. Through VBS, the church began coming in contact with more families who had children on the autism spectrum. Some of those families began attending church on Sunday mornings

**How the programs were organized.** Aimee coordinated volunteers for 1) The summer Vacation Bible School, or VSBS (Very Special Bible School), 2) The monthly *Special Saturdays*, and 3) The weekly buddy system for Sunday mornings (both Sunday school and children's church). A description of each of the programs is given here.

The first step in organizing the summer Bible school program was to train the volunteers. There were between 70 – 90 people who volunteered in this program. Aimee began with a biblical explanation of why the program was being offered and then presented an overview of how each day of VSBS would be divided into activities. She included an overview of the different diagnoses that volunteers might expect to see. Aspects of safety issues were covered, including the church's policy on having at least two caregivers at all times with each child. Aimee also included what she considered to be of utmost importance—that each child and parent would feel loved and cared for. The goal of the program was to build relationships—to form friendships with the children and families.

The VSBS lasted for three days from 9am - 12pm. At registration, each child was paired with one or two buddies who stayed with them the entire time. Siblings were encouraged to attend and they also had buddies. The buddies were there to greet them as they arrived. The children were divided into three groups that rotated to the different activities—crafts, games, and snack. Music and Bible time were offered in one main group. A “comfort room” was provided so

that any child who became over stimulated had a calming place in which to go. This room had a sandbox, different bead games, a rocking chair and a weighted blanket. The children were free to spend the whole morning there with their buddy, if they so chose. The end-of-day activities were designed to help the children relax. When parents came to pick up their child, the buddies gave a report of a positive experience or something the child had learned and enjoyed.

The first year the church adapted a curriculum from a regular VBS program from Lifeway Publishing Company. They used *Outrigger Island* which had a special needs section. Aimee modified it further until the curriculum was very simple and could be grasped by the youngest child that might attend. The second year, a member of the church who had a background in Montessori education wrote a curriculum specifically suited to the church's needs and resources. The VSBS grew from around 20 children the first year to about 40 children this last year.

The Special Saturdays also were mainly about forming friendships while offering a morning of respite to families; this included siblings. The program had grown to around 20 children. Each child, even siblings, had a buddy. The morning's activities included music time, Bible story, crafts and lots of playtime. The church had a large parachute, mini trampoline and centers set up for kitchen play, blocks, play dough and other gross motor activities. Around 30 volunteers participated in this program.

The children in *God's Love to You* were mainstreamed with their buddy into the regular Sunday school and children's church activities, except for Jacob. The Sunday school volunteers usually participated once a month, though some requested to be there more often. The volunteers for children's church rotated less frequently, once every eight weeks. At the time of the

interviews there were around six children that attended Sunday school and/or children's church and around 40 volunteers in the Sunday morning buddy system.

**Results on interview with the special-needs coordinator.** Aimee Parrish was the coordinator of the special needs ministry of Midtown Reformed Church's children's ministry department—a part-time position. Aimee was in her 40s with an exceptionally kind demeanor and listening ear. She had a degree and career in the medical field. She had attended Midtown Reformed Church for over 20 years and served in her position as coordinator for the past four years.

***Listening to parents.*** Aimee had a close relationship with each of the parents in *God's Love to You* which helped her to learn how to care for them more effectively. Connecting to the parents on an emotional level, she established and nurtured a relationship based on care and empathy. She said, "When the parents come in I try to greet each parent individually, give them a hug, how are you doing, you know, how's today going for you?"

She considered each of the parents to be experts who could teach her how to be more effective. She said, "I feel like we can learn from all of [the parents] and we can minister on different levels, whether it's support or whether it's, 'Teach me,' or, 'What can we do to come along side you.' Because she was so willing to listen, parents felt comfortable to share their needs with her. The main force behind the expansion of *God's Love to You* outside of Sunday mornings came from suggestions from parents.

But overall when something's been implemented it's been mostly from the input from the families and hearing a need and thinking, 'I wonder if we're supposed to be doing something different to listen or to care for them in a different way?' Like my friend saying 'Please, is there something you could do to give us a break?' [The *Special Saturday* program] was based on a family telling me a need. When I became not quite sure I could implement it, another mom of a child with special needs in our congregation



assured me it didn't need to have all the bells and whistles; we just needed to go forward and be willing. So with great opportunity of just trusting that God was doing that, we started out with probably just five or six children that came and volunteers, and it's just slowly grown. We're now finishing up our third year of it.

Communication from parents was also the impetus for the summer VSBS program.

I really felt like I was hearing from the families that some opportunities were needed for the summer. Again, not quite sure knowing what I needed to do. There are plenty of opportunities in the summer for children with special needs, especially in this county, but the piece I was hearing was the spiritual side.

Aimee discussed the direction that she would like to see the special needs program grow in the future. She was in the thinking stage of finding a way for the parents at the church who have children with special needs to be able to connect with each other.

I'd like to see a support type group for the parents, and that has not been implemented. I'm not quite sure how to get that off the ground, but I just sense just an opportunity for the families to have, whether it be monthly information. I mean they are in adult Sunday school classes so when their children are being cared for they're actually off getting biblical teaching with other parents. But I'm wondering if there's a need for a support group type thing or at least a database where each one knows the other one's in the church. The new family that's coming on board this Sunday had asked me, 'Do you have something that would allow me to know the other parents?' And I thought that's an amazing question because we all know each other, but she's coming on board new and wouldn't know, because they're not necessarily in the same Sunday school.

Another possible area for expanding this ministry is to become a resource to help other churches begin a special needs ministry.

I do feel passionate that it's important. I would love to see lots of churches doing it. I don't want to necessarily have the corner on the market. I don't have any threat to who I am or what we're doing here. I've had people call and say, 'Can we do this; how do we do it?' And I would say if I can do it, you can do it. So I would love to see that across the board.

***Ministering to the whole family.*** Aimee felt it was important to minister to the whole family, not just the child with special needs.

It definitely is not about one child. It's about a child of two parents or a child and siblings. What I've learned from observing is there are whole different layers of concerns

that some of these families may have that my family might not have experienced. So to take the child individually, I think, would be a great disservice because that child is who they are based on the relationships in their families, the family unit. A couple of our children are only children, but they still have a unique place in the family. So I definitely see it as a unit, as a whole package deal.

She also recognized the needs of siblings.

The siblings, I feel like they are a whole interesting group in themselves. One of the women who volunteers has an adult sister with special needs, and she has shared what it was like to grow up, great joy, with a child with special needs, but also great responsibility on her; and watching that process through her, knowing that the siblings all have a different role in the family.

Aimee learned some of the ongoing challenges that these parents face.

There might be an ongoing kind of grief when you hit each new milestone. It might be a realization that my child's not going to continue to progress. Or there's a heightened joy, not just grief, a heightened joy of seeing families of a child with a special need and then knowing how the family has had to do life differently where there are allowances made. So when I see a family come in, my heart first is to see what the child needs, how we can love the child, but knowing that it's a much bigger circle than that.

***Gathering support from the whole church.*** The church's ministry to families with children who have special needs could not be run on paid staff alone. It required the support of the church's leadership and it required a large number of volunteers from the congregation. As the programs provided by the children's ministry department expanded, more volunteers were needed, but Aimee was not sure if the church was willing to support this growth. After discussing this with the interim Christian Education director, Aimee approached the pastor.

I had gone to talk to [the pastor] in his office about the need for some more volunteers and whether we're going to be on board as a church. If we were, it's great; if we weren't, I just needed to know for what direction. And his response to me in a meeting was, "I think we should have a sermon on it. You should hear this from the pulpit."

The pastor organized an entire service around the church's special needs ministry.

Our pastor did a sermon out of the Book of James. There's a passage in there that talks about taking care of the widows and the orphans. He described that that passage is not exclusively widows and orphans, but it includes people with needs and special needs. He

went through that process, biblically what it looks like. And then he had a dad of one of our children speak, and then one of the main volunteers that's a buddy with her. She's one-on-one with her every week. It's unusual. And both of them gave a story about for the family of a child with special needs, how this particular person, Helen, had come alongside them with Alice, their daughter, since she was 18 months old. And really, that was one of the main reasons they had continued to stay at this church. And then Helen shared how God had invited her to come along and how Alice became one of the main reasons that she stayed at the church. And so it was a mutual blessing on both ends—of the buddy and the family.

To Aimee's surprise, many people from the congregation responded to the message and signed up to volunteer.

The congregation was very moved by hearing the true life stories. And we had tables set up after the service for anyone who wanted to volunteer. We had at that point just several sheets out, and probably 70 or 80 people came and just signed up and said, 'Please let me know more, please tell me how to get involved.' I had a training time after that immediately.

The Sunday morning buddy program during the Sunday school and children's church hours required 40-50 people. There were around 80 who volunteered with the Special Saturdays program and the summer activities.

***Jacob: An example of how the church meets special needs.*** Jacob was the only child in *God's Love to You* who did not attend regular Sunday school classes. He was the exception due to his dislike of crowded, noisy rooms. Therefore, a special room was designed for him. Aimee was his buddy, and had three men in the church who rotated being with her on Sunday mornings. This kept Aimee in compliance with church policy, but in addition, gave her needed support due to Jacob's occasional aggressive behaviors. The decision was made to have Jacob in a separate room based on input from his family after he did not do well in mainstream classes. He found the loud noises and bright lights of the Sunday school rooms to be extremely unpleasant and possibly painful. Aimee said, "We tried initially to go in and out [of a regular classroom], and it was hard for him. So his frustration might become louder. And his family seemed fine with him

not being in a main classroom.” At first the only available empty room was the CE office and that is where Aimee met with Jacob for Sunday school. However, “the lighting was over stimulating, and there were copy machines in there and paper and many things he couldn’t touch.”

A new CE director came on board and made it a priority to find a Sunday school room for Jacob.

A new director was hired in 2009 and one of her first things that she said is, ‘You need a room.’ And I thought, I love your heart, but there’s no space here. None of us have space. And she just went around the building and facilities and kind of had a vision and saw this one room that at one time held all of our craft supplies, construction paper, curriculum. It had a lot of shelves. And she just had a vision that if all of that was taken out, all the shelves were moved out, it actually was a fair-size room. She had done research on colors that would be soothing for a child with autism, put in new carpet, put in things that can be touched, just kind of a stimulation. And then there’s also a TV and a VCR. A big part of his morning is he likes to do the VHS tapes and hit forward and back. So that room has been just so amazing to have. He’s kind of free.

Jacob really enjoyed coming to Sunday school and enjoyed his special room.

I know that he comes and wants to be there, and he will often get up early on Sunday morning, and he’ll say, ‘I want to go to my Sunday school class.’ He beelines for that room on Sunday morning. He brings his big backpack full of all his VHS movies and just comes right in and plops himself down.

Before the transition to the new classroom, Jacob began showing some aggressive behavior (grabbing Aimee’s arm and hitting her). Aimee had been reluctant to ask the parents for help with Jacob’s behaviors. She was trying to “guard that time” for the parents to have an hour to worship. However, “when we were kind of at our height of his hitting behavior, and the mornings were just getting hard; my volunteers were saying this is hard.” Also, the CE director “was pretty firm about that if it got to a certain level we were going to have to ask them not to come, so I was determined, anything in my mind, to find out how or what we could get [his behavior] to a lower level.”

Aimee contacted the director of the regional office for *Joni and Friends*, an organization that helps connect persons with special needs and churches with each other. The director pointed out that Aimee had allowed this behavior to continue by unwittingly rewarding it. Aimee was surprised at first.

I said tell me how we did it, what did it? I didn't know if that was just the autism behavior coming out; he's frustrated. I wouldn't have allowed my own child to do that, but I thought with special needs maybe I need to make allowances. But I have learned I don't need to do that."

Aimee was encouraged to meet with the parents to explain what was happening and she and the parents came up with a plan for Aimee to call them when Jacob became unruly.

The times that he's started to hit back again, I'll say, 'You have a choice to make here, you can stay or you can go home.' And he always says, 'Stay.' And if he does it again, I don't like to repeat threats; I really do want to follow through, and I have called, especially initially. I just said, 'I'm going to need to call dad.' But if I say to him, 'If you hit again I'm calling dad,' he'll say to me, 'No hit Aimee,' or 'Sorry.' He goes 'I forgive you; I love you,' but he gets it. And so that behavior has come way down.

Aimee also went to his school to observe how the school system managed his behavior and implemented some of their techniques in Sunday school.

So I thought well he's in school Monday through Friday. I asked the parents, 'Would you care if I could just go and see if there's anything that we can learn to see if there's something in our morning that's very frustrating to him that I can't figure out and to see how he spends his day?' And they were willing for me to come in. And I learned some great things. I learned he didn't really get aggressive with them, and I learned almost everything was done as a positive incentive. I learned they're amazingly patient. They give a whole lot of positive feedback, lots of high fives. I implemented a token board, which is basically a picture of Jacob cut into eight squares with Velcro on the back on a strip. So when he did something great or we turned the video off, I said, 'Take a token Jacob,' and he put it so it eventually makes a picture of him. In the school system they reward him with movie time. Unfortunately for us, we already had started the movie time so it really wasn't a reward. Ours was kind of done backwards. But it just helped me to know to keep reinforcing the positive and keep learning, being willing to be patient, willing to just abandon all.

Aimee discussed Jacob's limited communication style. Her ability to understand him has increased the more time they have spent together.

He's verbal. He'll say phrases or he'll say sentences. Many times he'll quote something from a movie, a movie track or a movie phrase. When I ask him would you like your drink now, he says okay instead of yes. So I've learned over time that okay means yes. He's pretty clear when he can say no. Mostly it's phrases.

One of Jacob's primary ways of communicating is through videos. One of his preferred activities is fast forwarding the video to one of his favorite spots, and then hitting rewind and watching it over and over.

Sometimes it helps me to understand where he is [by watching the videos he brings]. Like if he's taking a paper towel tube and he's waving it around, and I'm watching the clip he's on, and he's seeing a cartoon with a battle scene. And I'm getting that he's acting out what he's seeing on TV. So sometimes I get a little clue of where he is on that day.

Aimee had an organized plan for Jacob's time in Sunday school that included religious instruction.

We do these questions on Sunday. They're called catechism questions, and it's basically a book that has the question and the answer. And then he has a workbook that he transcribes the answer from the question into the workbook. It'll say who is God? And over here the question was who is God, and it has the answer. Then he'll take that answer and put it over here. So he'll say to me on a Sunday, 'How many?' And I'll say, 'let's do ten today,' and I know he's talking about how many questions do I have to do. He's very clear on that.

She was flexible with the schedule, adjusting to Jacob's mood.

There's an area near our playground that has a brown covering, and he calls that a train station. So we'll go out and do our questions. I'll say, 'You want to go to the train station?' And he'll say, 'Okay.' So we'll go out on a bench over there. I try to enter his world, but he's in our world. It's just trying to figure out what it is.

Aimee commented on her perception on how much Jacob comprehends the catechesis.

I don't know how much of that he's processing, but we pray with him, and he has prayed with us. I guess my biggest objective would be to know that he's loved. The word of God is out there so I believe that when you hear the word of God, God can still use it in some form or fashion. Do I think he gets a lot of the questions? I'm not really sure about that, but I know that when we hit a question or I'll say something about God and I'll say, 'And God loves Jacob.' I'm not sure if I have a measuring stick to say what he's taken away. So my hope and desire is that he knows he's loved by humans, that God loves him even more.

She found activities for Jacob so that he helped contribute to the ministry of church.

Sometimes we've done different things where we've done jobs around here. They sell doughnuts, and we've taken the doughnut trash out. He's taken the money from the doughnuts and put it in the safe. I try to think of something that we can do that's a job where he has a purpose.

*Aimee: Theology of ministry.* Aimee's reason for reaching out to families with children who have special needs was rooted in her understanding of what it means to live out a Christian life.

I feel like I have opportunity to love as I've been loved from the Lord. I feel like I can just be hands and feet [of Jesus]. I feel like before our God that all of us have special needs, and really when we go before the throne He sees each one of us individually. I've been loved well and understand what it's like to be loved by God. I feel like I can walk that out in my life, whether it's hugs or respite or a craft being made, that I have opportunity to love as I've been loved.

She noted that the church had a lot to gain from welcoming families with special needs into their midst.

I think we have a lot to gain from incorporating the families that have children with special needs. I just think we're a more complete church. I don't think it makes us more disjointed. I think we have a better picture of what that looks like to be a kingdom church because it's clear in Scripture God says, let all the children come. Bring me the lame, bring me the blind.

In summary, Aimee's interview provided a history of the Midtown Reformed Church's ministry to children who have special needs. It evolved and grew over time in response to parents expressing their needs to the church. It had the support of the church's leadership and congregation to the point that they funded a part-time position dedicated to meeting the needs of families who have children with special needs. As coordinator of the special needs ministry, Aimee developed close, caring relationships with the parents to the point that parents felt comfortable sharing what their needs were. Aimee's goal was to minister to the whole family, not just the child with special needs. That perspective influenced her organizational design of the

volunteer program as well as her view of how to expand the program. The interview also included her theological perspective on why she was involved in this ministry and what she perceived the church's role to be.

**Results on interview with children's ministries director.** Martha Bridges was the Christian education (CE) director for Midtown Reformed Church. She was in this position for a little over a year. Prior to moving to this church, she was the CE director of a church in another metropolitan area in the same state for 18 years. She was a well-organized, business-like woman and was in charge of organizing and directing the Sunday school hour for the children of the church, as well as directing the weekday preschool program. She coordinated space and resources with the church's K - 12<sup>th</sup> grade academy.

The church where she came from in another part of the state was about the same size as the Midtown Reformed Church. They had a special needs ministry, although it was much smaller, with only three children and only offered during the Sunday morning. That ministry was requested by parents who were members and was run by a woman with her master's degree in special education. Those children had a dedicated room fixed with manipulatives and other items designed for them. However, the church had difficulty maintaining the program due to a lack of consistent volunteers.

Martha credited the success of *God's Love to You* to Aimee.

Aimee is the heart of the operation. I don't have any special needs training. In fact, I don't have children's education training at all. And it was great to see what Aimee had done because it was not something that I would have found on the map at all. They were mainstreaming kids in classrooms as well as the buddy system with particularly the autistic children that we have. It was just amazing to me to see how she coordinated [it all].

There are several families that come here because of what Aimee has put into practice and what she's done. And Aimee is so compassionate, plus she's a nurse. So she's just



sort of uniquely qualified for what she does, and she takes it very seriously. It can get overwhelming for her sometimes because she does care so much.

***Logistics and leadership structure.*** Martha discussed the logistics of maintaining a program that required a large number of volunteers. The first aspect was training Sunday school workers and volunteers how to work with children who have special needs.

Aimee briefs on how to handle some of the kids and we work with those parents as well to know how to handle those kids. They don't go in blind and they respond to discipline or, you know, being reeled back in. More of it, the harder part of it is not so much a discipline issue as it is just getting them to be part of the group. They tend to isolate themselves and be alone.

There was also the task of recruiting and maintaining enough volunteers to run the program.

It's a great system and yet it does take a lot of volunteers and I would say probably; and it's not perfect here. I mean it's hard. Especially men, it's hard to get men to do that. It takes a special man to be able to minister to kids like that, even for an hour. And that's probably why a lot of congregations don't do it. [It requires] a lot of manpower for a small group of kids and so a lot of people won't take that on.

Also, someone had to coordinate the schedules of the volunteers.

It's a huge job. Even though there aren't that many children it's still a big job because often you have two adults with a child and we have to minister to them both hours [Sunday school and children's church]. We do have some people that work every week with the same child, and then we have people that rotate with different children. It's a tough place to reach out to people because every situation is unique and different in special needs and with autistic children. If they are not able to mainstream, we have to have some of that one-on-one attention with them.

Martha saw the ministry structure as a hierarchy, with the pastor at the top. She felt all persons in leadership had to be in agreement to support a special needs ministry for it to be successful. "Well, you do have to have that to be successful. Children's ministry or special needs ministry; it goes from the top down." Martha discussed how the pastor also supported these ministries.

Our pastor, who is an interim, had [a special needs ministry] at his church that he retired from, a whole huge ministry up in [a large metropolitan city]. So he has a great heart for

it. He's a long-term interim for us. He's been here a little over three years and will probably be here another year and a half. He just has a huge heart for special needs.

Martha helped to provide a framework in which a special needs ministry could be successful. She saw Aimee as the hands-on person—the connector, while Martha was the person who provided resources that Aimee needed. Martha saw “the value that [*God's Love to You*] had within this community as a church and then in the greater community,” and felt her role was to provide the resources to the programs that were already underway.

For me this last year has kind of been getting acclimated to the system. They were really short on resources and places. One of the things I saw when I came in was they needed some resources, Aimee needed some backup. She was getting overwhelmed and just felt like she was the only one doing it and so I wanted to offer her that support, just trying to get resources for her, give her some special attention and make her feel supported and doing what she was doing. So that's kind of what I brought to the table.

As an example of providing resources, Martha explained the process of finding a dedicated room for Jacob. She could see that he was not going to be successful staying in the office with the fluorescent lights and so many things that he could not touch. She knew it was her role to find an appropriate space for him even though every available room was already in use.

You know that you can't put an autistic child in just any room. And when we did the room [for Jacob] it was a storeroom and we just took everything out of it, painted it, researched the colors and rooms that they like. We even went to disconnect the fluorescent bulb. In a year we've done so many changes, but just to get them a place that they can take Jacob because he was in an office room. So that was my main goal was just to have a place for him to go. And there's a lot more things that we're trying to offer, trying to get them more resources, tactile things. We've got a swing that we hope to put up and put a flat screen TV in there.

***Relying on the expertise of parents.*** Martha discussed the importance of parental involvement in special needs ministries. Neither she nor Aimee had any training in diagnosis, treatment, or any other issue pertaining to special needs. Everything they knew, they had learned from the parents. Martha said,

I know it was not something that I had any expertise in or any training in so we were all kind of feeling our way through it at my former church. And to come in and learn what I've learned from Aimee and other folks is just amazing.

Martha said the fact that their ministry was parent-driven was “gold” because every child had specific needs and no single template that would apply to Sunday school or any other respite program. When children began attending any of the church's special needs programs, at first it was quite time intensive and the parents spent a lot of time with Aimee, explaining how their child responded to certain situations and how they would like caregivers at the church to respond.

Every case is very specific. Every case is. We had so much work with one little girl. Her mother told us how we could show pictures and how we could get her to communicate. She wants to make her not be carried, that she has to stay down on the floor. [The child is always asking to be picked up.] Things like that. You know they have certain dolls that they like, they have certain toys that they like and so it's just always working in concert with the parents.

***The value of respite.*** Martha discussed the value of the church's special needs ministry as a respite to parents.

You just don't realize how valuable an hour together is for those parents. I didn't until I came to the first Special Saturday and heard from all these parents. It is a respite for them, but they also know how much their kids enjoy it and so that brings them joy as well. And I know the parents of those children spend so much time fighting for all their rights to be sure that they have everything they need. So it's just a constant battle for them. I think we can give them some sort of little help and we're glad to.

The *Special Saturday* program was not just offered to church attendees, but to parents in the surrounding community as well.

On *Special Saturdays*, which Aimee does once a month, we minister to the other children and their siblings and that special needs community. They don't necessarily go here, but they come to Special Saturdays and it gives parents a two-hour respite and the kids **love** it. We have one family that doesn't tell their daughter she's coming until that morning because she doesn't sleep the night before because she's so excited. You hear stuff like

that and you just think this is a great thing. So that's another way that you can minister and reach out and just live the Gospel in front of the community even if they're not members of your church.

***Vision for the future.*** In spite of the desire to reach out to the community and minister to families who have children with special needs, Martha did not feel the church had the resources to absorb more families into their congregation. She responded to the question on what the church would do if they received an influx of ten families into the *God's Love to You* program.

I think that would put Aimee over the edge and me too. If that happens you would have to have a full-time person on staff who is constantly recruiting, learning, studying. Aimee is part-time so she does this on a very limited number of hours even though she probably does more hours than she lets me know about. But the people I think who do it on a large scale and do it really well are people who have a whole area, rooms, resources and people dedicated to that and right now we don't have that.

However, Martha did have a vision for future development as more time and resources become available. She discussed her future goals for the special needs ministry.

Well I'd like to see it meet some more needs. Not grow by leaps and bounds immediately because I'm still in the learning process, but to make provisions space wise, to think on a little grander scale, get Aimee used to that. Maybe look at finding someone else part time to help her with things – because it is a part-time job for her – so that she doesn't feel so overwhelmed when we do get new people in and she has to meet those needs. It's a job hunting people down and saying will you work with this person. The interesting thing is once they've worked with Aimee and the kids they're usually hooked.

[I would like to see some programs that support the families] a ways down the road and again it would probably need to be an expanded area of the children's ministry, again a full-time staff member. Aimee has a large family herself and so traveling to conventions and things like that is just not something Aimee can do. I have not been able to do it either this first year because we've had so many changes and the whole rest of the ministry, plus I have the preschool over here. There are a lot of areas that we can explore and do better at in that, but it's going to be a matter of time, people and just resources to do that, for parents especially.

They haven't done that and I know basically here [in this county] there is a community of special needs parents that meet together and do things together, and I've not been part of that. That kind of thing being out in the community with those parents and those kinds of things and Aimee does what she can. But again just time and resources. We have that side of the children's ministry too where we minister to children and we minister to parents.

We call it the Deuteronomy Principle where we help equip parents in the task of raising kids. So we are focused on both things, and so yes, that can translate easily over into the special needs parents. But that's something that we haven't done yet.

***Martha: Theology of ministry.*** Martha discussed her theology of care for children with special needs and their families.

I'm a huge lover of covenant family, which means that I'm as responsible to help you raise your children as you are to help me raise mine. I'm as responsible to help you survive a flood as you are to help yourself. So the responsibility comes in that we are part of a larger family. We are responsible and just because something doesn't fit, is uncomfortable sometimes or doesn't fit a traditional mold in a church, you can't turn your back on it. We weep with those who weep, celebrate with people who have things to celebrate with and you meet needs as best you can, particularly in the children's ministry. You never know when you're going to affect a life and it's not our job to figure out how and when that's going to happen. Our job is to preach the Gospel to the kids and that's through word and deed. It's just a day-to-day thing. It can change a child's life, it can change an adult's life. You just never know. And so it's just part of the process as far as I'm concerned; part of the responsibility of being in covenant family.

In summary, Martha expressed her view that she provided support for the structural framework of the church's Christian education ministries. She immediately saw the value of *God's Love to You* and saw that Aimee required more support and resources for her program to be successful. She did not feel that she had to be the expert, but relied on a network of experts within the church, which included the parents of children who had special needs. This view influenced her view that this program will need more space, paid staff and volunteers if it is to support future growth. She also included a discussion of her theology of ministry and the role of the church in providing support programs for families who have children with special needs.

### **Summary of Research Questions 3 – 4 Results**

To answer the central question of this study, what types of support did the Midtown Reformed Church provide to families with children who had special needs? The church provided respite through three programs. On Sunday mornings during the Sunday school and children's

church hours parents were able to leave their children with competent, caring adults and attend religious services. One Saturday morning a month, *Special Saturdays*, provided a couple of hours of respite, and during the summer VSBS and occasional activities, such as family movie night or a sock hop gave families support.

By what process did Midtown Reformed Church become aware of the need to support families who have children with a diagnosis on the autism spectrum? The church became aware of this need through close relationships. *God's Love to You* was started when friends of a mother noticed she was not attending church regularly any more. This program grew to the point where the church provided a part-time position for someone to coordinate the church's response to these families. Because of the close relationships between Aimee and parents of children with special needs, the parents felt free to offer suggestions which resulted in providing more opportunities for respite in a church setting. Aimee researched these suggestions and took them to the CE director and the pastor to make the larger church family aware of what types of support these families needed. See Figure 6.2 for a visual representation of this process.

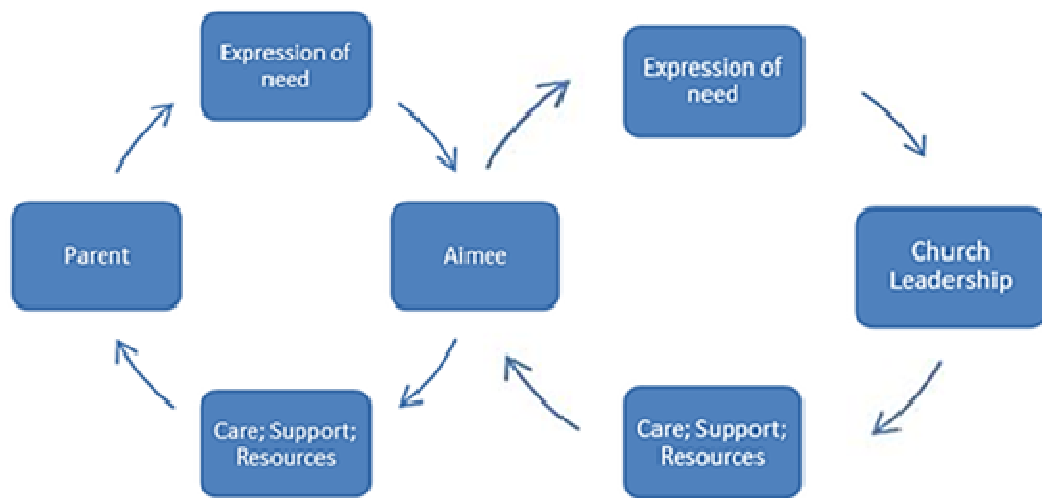


Figure 4.2 Model of church process for meeting the needs of families with children on the autism spectrum

How did the church design programs to support families with a diagnosis on the autism spectrum? Programs were designed by gathering information from several sources. Both Aimee and Martha spent time researching information on various diagnoses. Parents were used as an expert resource. Other programs offered by churches, schools, and parachurch ministries such as *Joni and Friends*, were consulted.

In addition, programs were designed because the entire leadership structure was involved. Programs could not be run on paid staff alone. Volunteers from the congregation were a necessity, and it takes many volunteers to run a successful special needs ministry. Church members heard from the pastor on the importance of providing this ministry. The CE director provided a framework which supported Aimee by making sure she had the space and resources she needed. Any future growth would have to be supported by more resources and volunteers.

Finally, the theology of ministry of Aimee and Martha was the wellspring from which flowed the ideas on how to design these programs. Aimee ministered to families out of a desire to show the love of God, to be the hands and feet of Christ and to help make the church “more complete.” Martha ministered out of her understanding of the Church as a covenant family, where she was responsible to support other members of the church. Both of these theologies meshed well with the pastor’s views and he shared this view with the rest of the congregation.



## **CHAPTER 5**

### **QUANTITATIVE RESULTS**

The central question of this study is, “What types of support do churches provide when a member is diagnosed with ASD and what is the impact of this support on the family?” This was a mixed methods study, consisting of two parts. Questions 1 – 4 were answered through qualitative data collection and questions 5 – 9 were answered through quantitative data collection. In order to answer the last five questions, a survey was conducted on churches in the mid-size metro area for data on church characteristics that correlate with ASD programs, types of programs offered, prevalence rates of attendees who have children with ASD, and the level of understanding clergy or church staff have on ASD. Results of these data are presented in this chapter.

#### **Findings on Research Questions 5 – 9 from Quantitative Data Analysis**

In order to understand what churches in the metro area were doing to minister to families who have children with special needs, the following questions guided the development of the church questionnaire and autism awareness survey. Results of these questions are reported in this section:

5. What characteristics of churches correlate with providing programs for families with a child with ASD?

6. What proportion of churches has a program specifically to support families of children with ASD?
7. How do ASD prevalence rates of attendance in churches compare with IDEA statistics?
8. What resources are churches providing for families with a child who has ASD?
9. What is the degree of awareness of ASD among church staff?

## **Overview of Study Results**

This section contains an overview of the study results for Research Questions 5 – 9. An explanation is given of how and why churches were categorized into denominational groupings. Also, preliminary analyses yielded descriptive statistics on the sample of churches and on the churches that responded to the interview.

**Descriptive statistics on the population of churches.** In order to fully understand the sample of churches chosen for this study, information on denominational status from the population of the 1,100 churches in the mid-size metropolitan area was entered into an SPSS file to generate descriptive statistics in the form of frequency tables. Many of the denominations had a small number of respondents and others had a high degree of respondents. Church denominations were grouped into six categories in order to increase group size for some and even out group size for others. The six categories are as follows:

1. Liturgical (Catholic, Episcopal, Orthodox)
2. Mainline (Christian, Community, Disciples of Christ, Lutheran, Presbyterian, Methodist - including African Methodist Episcopal Zion, Christian Methodist Episcopal)
3. Evangelical (Bible Fellowship, Church of God – Anderson, IN, Church of Christ, and Seventh Day Adventist)

4. Baptist (Freewill Baptist, Missionary Baptist, Primitive Baptist, and Southern Baptist)
5. Pentecostal (Assemblies of God, Apostolic, Church of God – Cleveland, TN, Church of God in Christ, Foursquare, United Pentecostal, and Vineyard)
6. Independent (Independent churches were comprised of individual congregations that did not identify with any denomination)

Christian denominations can be categorized in a variety of ways. The Catholic, Orthodox and Episcopal denominations were grouped together in the liturgical category. As non-Protestant churches, they share a common adherence to a liturgy and a common style of worship. Mainline churches were chosen according to Protestant denominations that were noted as established Christian churches by the beginning of the 1800s in the US (McKinney, 1998). This category also includes the direct offshoots of these established denominations. Evangelical churches are Protestant, non-mainline denominations that share a conservative view of the Bible and culture. While many Baptist congregations would identify as evangelical, the large representation of Baptists in this region merited its own category. Pentecostal churches may also be identified as evangelical, but were given their own category due to significant representation and because of their distinct theological emphasis on the role of the Holy Spirit. Independent churches vary in their theological outlooks. However, they share the trait of not relying on an overarching structure or common form of church governance. Table 5.1 shows the populations of Christian churches in the metro area according to groups.

Table 5.1

## Population of Churches in the Area according to Group

Group	Frequency	%
Liturgical	60	5.4
Independent	114	10.3
Pentecostal	128	11.5
Evangelical	214	19.3
Mainline	243	21.9
Baptist	351	31.6
Total	1110	100.0

**Descriptive statistics on the random sample of 300 churches.** Information from the 300 churches randomly chosen for the sample in this study was entered into an SPSS file in order to generate descriptive statistics on how the churches responded. The responses were as follows:

- Interviewed – Churches that agreed to participate in the interview
- Refused interview – Churches that answered the phone, but declined to participate
- Answering Machine – The researcher called each of these churches at least 5 times and each time only an answering machine responded to the call
- Phone Disconnected – The phone number was disconnected or no longer in service

Of the 300 churches in the random sample, 125 agreed to answer at least the demographic section of the questionnaire for a total response rate of 41.7%. There were 45 (15%) respondents who refused the interview, 84 (28 %) churches that only had answering machines and therefore no one from that church could be reached by phone to interview, and 46 (15.3%) of the churches had their phone disconnected or the number was no longer in services. In order to determine if there was a difference in response rates among denominational categories, a chi-square test was run. A significant difference was found among denominational categories in how they responded to the phone survey,  $\chi^2(5, N = 300) = 5.85, p = .32$ , with liturgical churches more likely to agree

to an interview. However, the sample size of liturgical churches was much smaller than for the rest of the categories. Table 5.2 shows how churches responded to the survey according to individual denomination. Table 5.3 shows how churches responded to the survey according to denominational category.

Table 5.2

Types of Responses to the Phone Survey according to Denomination

Denomination	Interviewed		Refused interview		Answering Machine		Phone Disconnected	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
AME Zion	1	0.3	1	0.3	1	0.3	1	0.3
DOC/Xn/Comm	6	2.0	2	0.7	1	0.3	4	1.3
Lutheran	4	1.3	1	0.3	0	0.0	0	0.0
Presbyterian	9	3.0	3	1.0	6	2.0	2	0.7
Methodist	7	2.3	3	1.0	9	3.0	4	1.3
Evangelical	3	1.0	0	0.0	5	1.7	1	0.3
Nazarene	4	1.3	0	0.0	5	1.7	0	0.0
Church of Christ	16	5.3	4	1.3	8	2.7	6	2.0
Seventh Day Adv	2	0.7	1	0.3	4	1.3	0	0.0
Orthodox	0	0.0	2	0.7	1	0.3	0	0.0
Catholic	5	1.7	1	0.3	1	0.3	0	0.0
Episcopal	7	2.3	0	0.0	3	1.0	0	0.0
Freewill Baptist	4	1.3	0	0.0	0	0.0	3	1.0
Primitive Baptist	1	0.3	0	0.0	2	0.7	2	0.7
Missionary Baptist	2	0.7	4	1.3	7	2.3	2	0.7
Southern Baptist	29	9.7	11	3.7	17	5.7	3	1.0
Assemblies of God	5	1.7	2	0.7	0	0.0	0	0.0
C of G (Cleveland)	4	1.3	1	0.3	3	1.0	0	0.0
Apostolic	1	0.3	0	0.0	4	1.3	1	0.3
COGIC	0	0.0	0	0.0	2	0.7	4	1.3
Pentecostal	2	0.7	1	0.3	2	0.7	6	2.0
C of G (Anderson)	1	0.3	0	0.0	0	0.0	0	0.0
United Pentecostal	1	0.3	2	0.7	0	0.0	0	0.0
Independent	11	3.7	6	2.0	8	2.7	7	2.0
Total	125	41.7	45	15.0	84	28.0	46	15.3

Table 5.3

Types of Responses to the Phone Survey according to Categories

Denomination	Interviewed		Refused Interview		Answering Machine		Phone Disconnected	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Mainline	27	9.0	10	3.3	17	5.7	11	3.7
Evangelical	26	8.7	5	1.7	17	5.7	7	2.3
Liturgical	12	4.0	3	1.0	5	1.7	0	0.0
Baptist	36	12.0	15	5.0	26	8.7	10	3.3
Pentecostal	13	4.3	6	2.0	11	3.7	11	3.7
Independent	11	3.7	6	2.0	8	2.7	7	2.3
Total	125	41.7	45	15.0	84	28.0	46	15.3

**Descriptive statistics on the 125 churches interviewed.** The data from the 125 churches that agreed to the interview were entered into an SPSS file to generate descriptive statistics. Frequency tables were generated on all sections of the data to confirm the minimum, maximum and the range for each variable. Table 5.4 depicts the churches according to denominational affiliation. This frequency table shows the most prevalent denominations represented were Church of Christ ( $n = 15$ , 12%), Independent churches ( $n = 13$ , 10.4%) and Southern Baptists ( $n = 29$ , 23.2%).

Table 5.4

## Denominational Affiliation of Churches that Participated in Questionnaire

Denomination	Frequency	%
AME Zion	1	0.8
Church of God (Anderson)	1	0.8
Primitive Baptist	1	0.3
Apostolic	2	1.6
Seventh Day Adventist	2	1.6
Missionary Baptist	2	1.6
Church of God (Cleveland)	4	3.2
Freewill Baptist	4	3.2
Lutheran	4	3.2
Nazarene	4	3.2
Pentecostal	4	3.2
Assemblies of God	5	4.0
Catholic	5	4.0
Episcopal	7	5.6
Methodist	7	5.6
DOC/Community/Christian	8	6.4
Presbyterian	8	6.4
Independent	13	10.4
Church of Christ	15	12.0
Southern Baptist	29	23.2
Total	125	100.0

Table 5.5 represents the denominational affiliation of churches divided into groups.

Baptist was the most represented denomination among the groups represented (n = 85, 28%).

Table 5.5

## Denominational Groups

Group	Frequency	%
Liturgical	12	9.6
Independent	13	10.4
Pentecostal	18	14.4
Evangelical	19	15.2
Mainline	28	22.4
Baptist	35	28.0
Total	125	100.0

Zip code was used as a socioeconomic measure. The zip codes were grouped into the following categories: Urban, North, South, East, West, Southwest, and Southeast. The Southwestern zip codes contain the highest property values in the metro area ([www.zip-codes.com](http://www.zip-codes.com)). Table 5.6 shows how churches were represented according to these zip code groups, with the Southwestern zip codes having the most representation (n = 40, 32%).

Table 5.6

## Zip Code Groups

Group	Frequency	%
Southeast	7	5.6
North	13	10.4
East	15	12.0
South	15	12.0
West	15	12.0
Urban	20	16.0
Southwest	40	32.0
Total	125	100.0

A variety of church staff members provided answers to the questionnaire. The majority of respondents (62.4%) were in a ministerial capacity such as pastor (24%, n = 30), associate



minister (n = 9, 7.2%), children's pastor (n = 28, 22.4%), or Christian education director (n = 11, 8.8%). The remaining respondents were administrative assistant/secretarial staff (n = 42, 33.6%) or in another capacity (n = 5, 4%).

An overwhelming majority of the churches that responded to the survey identified as primarily Caucasian (n = 97, 77.6%). Other churches identified themselves as primarily African American (n = 13, 10.4%) or primarily mixed ethnicity (n = 14, 11.2%). One church identified as primarily Hispanic (.8%).

Churches were asked the number of full-time staff members they supported. Responses ranged from only one person on staff up to 85 (Mean = 7.14, Median = 3, Mode = 1). Table 5.7 represents staff members according to groups.

Table 5.7  
Number of Full-time Staff Employed by Churches

Group	Frequency	%
1	30	24.0
2 – 4	44	35.2
5 – 10	18	14.4
11 – 20	9	7.2
20 +	10	8.0
Did not answer	14	11.2
Total	125	100.0

Average Sunday morning attendance ranged from 30 to 10,000 (Mean = 743.59, Median = 270, Mode = 100). This variable was re-coded into four groups. Table 5.8 represents the average attendance groups.

Table 5.8

## Average Attendance by Groups

Average Attendance	Frequency	%
100 or less	31	24.8
101 – 500	53	42.4
501 – 1999	31	24.8
2000 +	10	8.0
Total	125	100.0

Churches were also asked for the average number of children that attend on Sunday morning.

Average children's attendance ranged from 3 to 3,000 (Mean = 194.29, Median = 50, Mode = 20). Table 5.9 shows children's average Sunday morning attendance according to groups.

Table 5.9

## Average Children's Attendance by Group

Average Attendance	Frequency	%
30 or fewer	44	35.2
31 – 175	48	38.4
176 – 500	21	16.8
501 +	12	9.6
Total	125	100.0

Staff members of 21 churches responded that the minister addressed the topic of special needs from the pulpit, and 31 of the respondents had formal training in the area of special needs and families. Of those respondents who had formal training, most of it was from college or graduate degrees in education (n = 11), social work (n = 1), or counseling (n = 2). Five respondents had formal training provided from a church organization.

### Results for Research Question 5: What Characteristics of Churches Correlate with Providing Programs for Families with a Child who has ASD?

Chi-square tests were performed to determine whether or not a program for children with special needs (and more specifically, for children on the autism spectrum) was more likely in churches with certain demographic characteristics. There was no significant relationship between children with special needs attending a church and church denominational group,  $\chi^2 (5, N = 125) = 5.05, p = .41$ . Neither was there a significant relationship between children on the autism spectrum attending a church and church denominational group  $\chi^2 (5, N = 125) = 3.59, p = .61$ . Figures 5.1 and 5.2 show crosstabulation charts representing these comparisons.

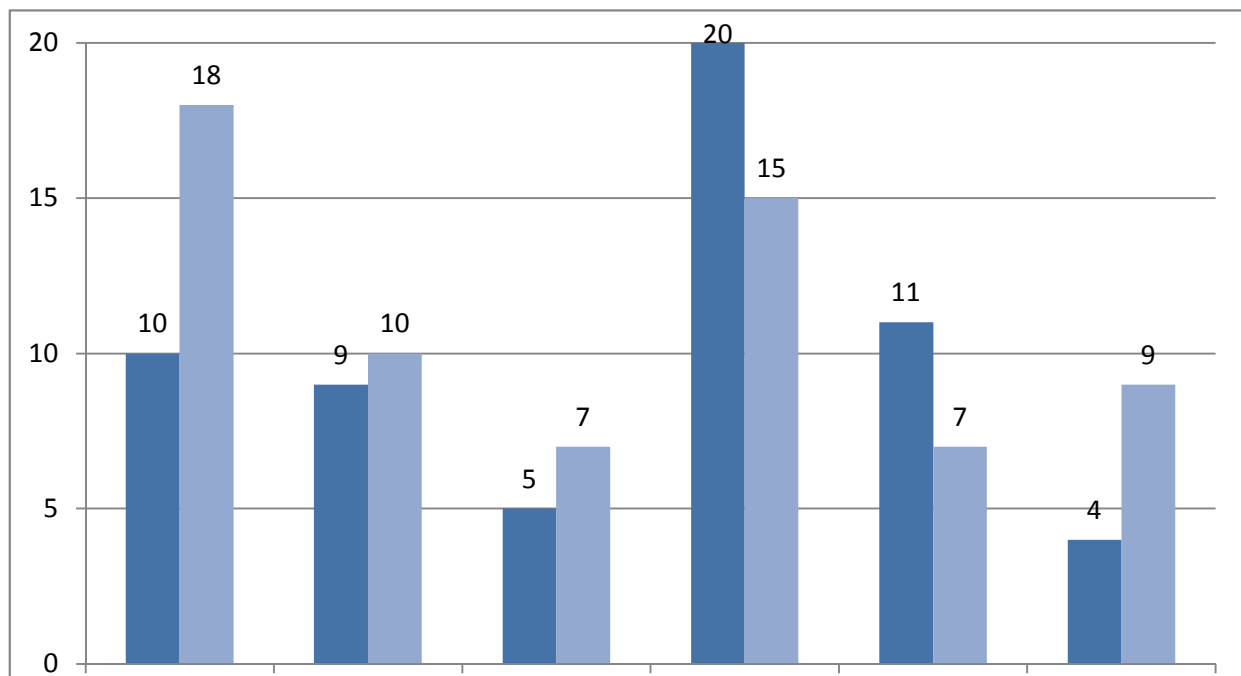


Figure 5.1 Denominational group according to children with special needs attending

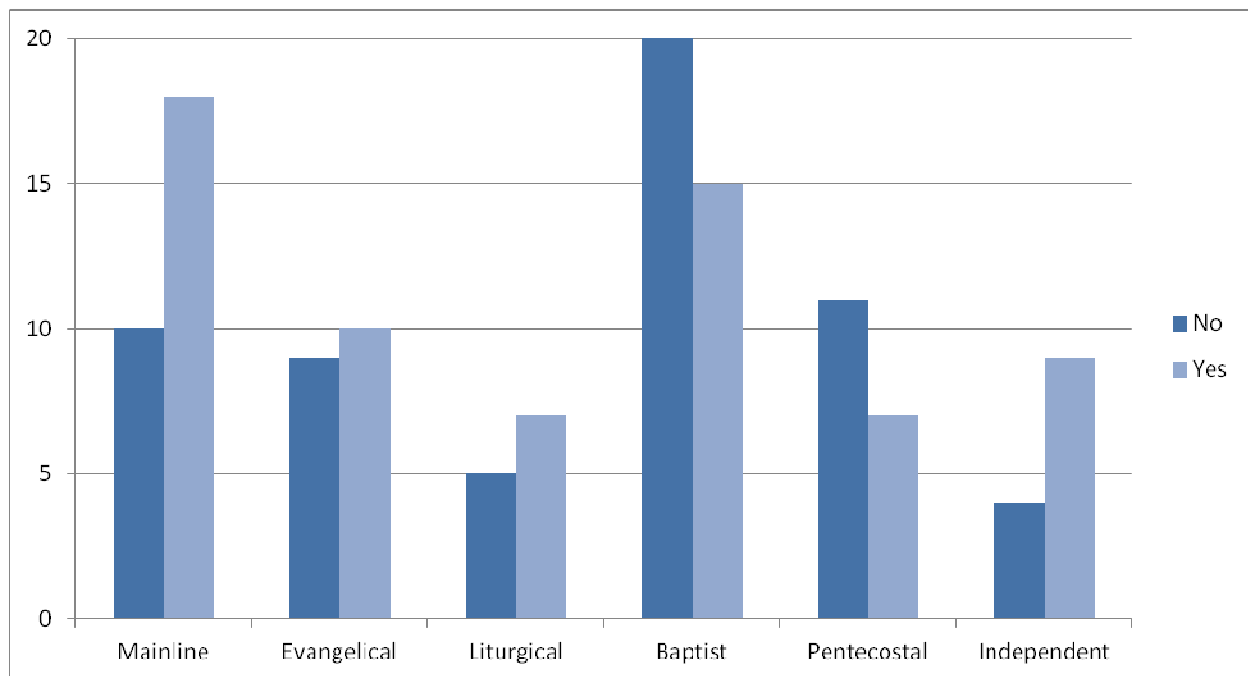


Figure 5.2 Denominational group according to children with ASD attending

There was no significant relationship between having a particular zip code and providing a program for children with special needs,  $\chi^2 (6, N = 125) = 8.37, p = .21$ . However, there was a significant relationship between churches' zip code and providing a program for children with autism,  $\chi^2 (6, N = 125) = 13.13, p = .03$ , with the wealthiest zip codes significantly more likely to provide special programs.

Churches able to hire two or more full-time staff were significantly more likely to have a child with special needs in the congregation,  $\chi^2 (4, N = 125) = 28.25, p = .00$ , and were significantly more likely to have children on the autism spectrum in the congregation,  $\chi^2 (4, N = 125) = 28.12, p = .00$ . Churches able to hire five or more full-time staff were significantly more likely to provide services for children with special needs,  $\chi^2 (4, N = 125) = 24.84, p < .00$ , and to provide services for children on the autism spectrum,  $\chi^2 (4, N = 125) = 27.52, p = .00$ .

Churches with congregations of more than 100 people were significantly more likely to have children with special needs attending,  $\chi^2 (3, N = 125) = 37.37, p = .00$ , and to have a program for children with special needs,  $\chi^2 (3, N = 125) = 37.28, p = .00$ . Churches with congregations of more than 500 were significantly more likely to have children on the autism spectrum attending,  $\chi^2 (3, N = 125) = 38.79, p = .00$ , and were significantly more likely to have special programs for children on the autism spectrum,  $\chi^2 (3, N = 125) = 41.33, p = .00$ . See Table 5.10 to see the comparison of children with special needs attending according to congregation size and Table 5.11 to see the comparison of children on the autism spectrum attending according to church size.

Table 5.10

Attendance of Children with Special Needs according to Church Size

Church Size	Special Needs		Total
	No	Yes	
0 – 100	22	9	31
101 – 500	14	39	53
501 – 1999	2	29	31
2000 +	0	10	10
Total	38	87	125

Table 5.11

Attendance of Children with ASD according to Church Size

Church Size	ASD		Total
	No	Yes	
0 – 100	26	5	31
101 – 500	29	24	53
501 – 1999	5	26	31
2000 +	0	10	10
Total	60	65	125

Pastors who addressed the topic of special needs from the pulpit were significantly more likely to have children on the autism spectrum in their congregations  $\chi^2 (1, N = 125) = 5.92, p = .02$ . Also, 19 respondents said they had some type of formal training in working with families who had children with special needs. The churches associated with the respondents who had some type of formal training were significantly more likely to have children with special needs in their congregations  $\chi^2 (1, N = 125) = 11.17, p = .00$ , as well as children on the autism spectrum attending  $\chi^2 (1, N = 125) = 20.34, p = .00$ . Table 5.12 lists the types of formal training that the respondents noted.

Table 5.12  
Types of Formal Training

Type	Frequency	%
Social work degree	1	.8
Denominational training	5	4.0
Counseling degree	2	1.6
Education degree	11	8.8
Did not answer	81	64.8
Total	125	100.0

#### **Results for Research Question 6: What Proportion of Churches has a Child or Children with ASD in their Congregation?**

Churches were asked whether or not they had any children with special needs who attended the congregation. Frequency tables were generated to confirm the minimum, maximum and the range for this variable. The majority of churches reported that they did have a child or children with special needs in the congregation ( $n = 87, 69.9\%$ ). Of these churches, the range of

children with special needs attending was 1-60 (Mean = 8.48, Median = 4, Mode = 1). Table 5.13 shows the number of children with special needs according to group.

Table 5.13

Average Children with Special Needs Attending by Group

Average Attendance	Frequency	%
0	39	31.2
1 – 3	30	31.2
4 – 9	24	19.2
10 – 19	14	11.2
20 +	9	7.2
Total	125	100.0

Several types of special needs were identified by the churches that were surveyed. More churches listed autism as a special need than any other single diagnosis, and more children were reported to be on the autism spectrum than any other diagnosis. Table 5.14 lists the types of special needs, the number of churches that identified each category of special need, and the number of children overall that were reported with each diagnosis. Autism was by far the largest category.

Table 5.14

## Types of Special Needs Identified by Churches

Diagnosis	Number of Churches	Number of Children with that Diagnosis
Autism Spectrum	65	259
ADHD	14	91
Intellectual Disability	32	74
Cerebral Palsy	31	72
Deaf	8	50
Chromosomal Disorders	16	25
Reactive Attachment	4	14
Diabetes	7	14
Developmental Delay	13	18
Cancer	7	12
Down Syndrome	17	30
Epilepsy	5	9
Spina Bifida	7	7
Traumatic Brain Injury	4	6
Cystic Fibrosis	3	5
Fetal Alcohol Syndrome	1	5
Learning Disability	3	7
Paralysis	3	5
Feeding Tube	3	4
Muscular Dystrophy	3	3
Social Anxiety	1	3
Blind	2	2
Medically Fragile	2	2
Tourette Syndrome	2	2
Acheiropodia	1	1
Hydroencephaly	1	1
Kidney Disease	1	1
Meningitis	1	1
Multiple Sclerosis	1	1
Total	Overlapping	724

Of the 87 churches who reported having children with special needs in their congregation, 65 identified having a child or children with an autism spectrum diagnosis in their



congregation. This represents about half of the 125 churches surveyed who identified children with autism in their congregations (n = 65, 52%). The number of children with autism in a congregation ranged from 1 to 25 (Mean = 3.94, Median = 2, Mode = 1). Table 5.15 shows the frequency with which churches identified these children in their congregations.

Table 5.15

Frequency of Children Attending on the Autism Spectrum

Number of Children with ASD	Number of Churches	% of Total Churches Interviewed
0	60	48.0
1	17	13.6
2	16	12.8
3	8	6.4
4	8	6.4
5	6	4.8
6	2	1.6
7	2	1.6
10	2	1.6
15	1	.8
17	1	.8
20	1	.8
25	1	.8
Total	65	100.0

**Results for Research Question 7: How do ASD Prevalence Rates of Attendance in Churches Compare with IDEA Statistics?**

As of September 2007, the metropolitan school system reported 74,155 children enrolled in their 133 schools. Of the 9,156 eligible for special education services, 277 students had a diagnosis of autism (1.5% of the metro school population) (Nashville Metro Public Schools, 2007). This compared to 2.8% of children with autism served under IDEA statewide in Tennessee, and 3.33% nationwide in the fall of 2006 (U.S. Department of Education, 2006).

Tables 5.16, 5.17, and 5.18 show 2006 IDEA statistics as reported by the state of Tennessee and the 2006-2007 IDEA statistics as reported by the metro public schools and the Southwest adjoining county school systems (Offices of Research and Education Accountability, 2009; U.S. Department of Education, 2006).

Table 5.16

2006 IDEA Statistics for the State of Tennessee

Category	<i>N</i>	%
Total Students with ASD	4,019	.4
Total Students with Special Needs	120,925	13.3
Other Students	785,056	86.3
Total Student Population	910,000	100.0

Table 5.17

2006-2007 IDEA Statistics for Davidson and Williamson Counties

Diagnosis	Nashville Metro	Williamson Co.	Franklin City	Total
Learning Disability	2,310	999	137	3,438
Intellectual Disability	863	102	0	965
Speech/language Disability	2,161	655	164	2,980
Emotional Disability	575	58	0	633
Autism	599	238	41	878
Health Impaired	922	415	28	1,365
Orthopedically Impaired	64	31	0	95
Hearing Impaired	151	20	7	178
Blind	68	13	0	81
Multiple Disabilities	31	68	7	106
Developmental Delay	877	183	72	1,132
Traumatic Brain Injury	23	10	0	33
Total	8,444	2,784	476	11,695

Table 5.18

2006 – 2007 IDEA percentages for Davidson and Williamson Counties

	Nashville Metro	Williamson Co.	Franklin City	Total
% of ASD of Total	1%	1%	1%	1%
% of Special Ed of Total	11%	9%	12%	11%
% of ASD w/in Special Ed	7%	9%	9%	8%
Total Student Population	74,000	31,000	3800	108,800

Frequency tables were generated in SPSS to obtain the number and percentage of children with special needs and autism that were reported by churches in the survey. Table 5.19 displays statistics from the church questionnaire.

Table 5.19

Special Needs and ASD Statistics from 2010 Church Questionnaire

Category	Number	%
Total Children with ASD	259	1.0
Total Children with Special Needs	724	3.0
Other Children	23,303	96.0
Total Children in Survey	24,286	100.0

The IDEA statistics showed that from 9% to 12% of children in various schools in the metro area are served through a special needs designation and about 1% of those students have a diagnosis of autism. The rate of autism is higher in the metro area (1%) than for the state (.4%). Data derived from the church questionnaire showed that in comparison with IDEA statistics a much smaller percentage of children (3%) in the congregations in and around the metro area were identified as having a special need of some kind. However, children on the autism spectrum were identified as attending church at a comparable rate (1%) with IDEA statistics for the metro area.

### **Results for Research Question 8: What Resources are Churches Providing for Families with a Child who has ASD?**

Descriptive analyses were performed to calculate frequencies and percentages to address this question. Of the 125 churches surveyed, 54 (43.2%) identified that they offered some type of special services designed to meet the needs of children on the autism spectrum. The special services are listed in table 5.20.

Table 5.20  
Types of Modifications for Children with Special Needs

Type	Frequency	%
Connect with Community Resources	5	4.0
Respite (Formal)	6	4.8
Special Curriculum	7	5.6
Separate Classroom	14	11.2
Support Groups	14	11.2
Counseling	21	16.8
Changes to Sunday school Room	24	19.2
Respite (Informal)	24	19.2
Special Training for Workers	31	24.8
Buddy System	43	34.4
Sunday school Changes	57	45.6

### **Results for Research Question 9: What is the Degree of Awareness of ASD among Church Staff?**

Of the 125 churches that agreed to give demographic information, 75 churches also agreed to answer the survey on autism awareness. The response rate for the autism survey was 25% of the total 300 churches in the sample. The Autism Awareness Survey consisted of 20 true

statements about autism and is found in Appendix J. Respondents were asked to respond in Likert-scale statements on how familiar they were with the statements as follows:

- 4 – Very familiar with the statement
- 3 – Somewhat familiar with the statement
- 2 – Somewhat unfamiliar with the statement
- 1 – Very unfamiliar with the statement.

To examine whether church staff in various denominational groups differed in their willingness to answer, the Autism Awareness Survey, a chi-square test was run comparing respondents according to denominational group. No significant difference was found,  $\chi^2 (5, N = 125) = 3.19, p = .68$ . However, respondents were significantly more likely to answer the Autism Awareness Survey according to the following variables:

- Churches with more than 500 attendees,  $\chi^2 (3, N = 125) = 11.83, p = .01$
- Churches with more than 5 full-time staff,  $\chi^2 (4, N = 125) = 14.26, p = .01$
- Children with special needs attending the church,  $\chi^2 (1, N = 125) = 15.13, p = .00$
- Children with autism attending the church,  $\chi^2 (1, N = 125) = 16.16, p = .00$

Table 5.21 shows the mean scores and standard deviations for each of the items on the autism awareness survey.

Table 5.21

## Descriptive Statistics for Results of the Autism Awareness Survey

Statement	Mean	Standard Deviation
1. Autism is not caused by bad parenting	3.95	.22
2. The term 'autism spectrum'...	3.64	.56
3. Prevalence rates	3.00	1.10
4. Ratio of boys to girls	3.28	.86
5. Difficulty making eye contact	3.61	.70
6. Difficulty making friends	3.69	.55
7. Difficulty understanding social rules	3.71	.46
8. Parroting back words or phrases	3.67	.50
9. Difficulty understanding gestures	3.63	.56
10. Limited or no creative play	3.49	.74
11. Hand-flapping	3.59	.72
12. Giggle fits	3.49	.76
13. Meltdown tantrums	3.65	.60
14. Sensitivity to lights	3.01	1.28
15. Sensitivity to sounds	3.12	1.19
16. Sensitivity to touch	3.29	1.12
17. Parents have increased stress	3.01	1.11
18. Parents have lower support	2.87	1.19
19. Parents have higher divorce	2.68	1.23
20. There are training materials for churches	2.56	1.22

Scores that had a mean of 3 or above indicated the majority of respondents were familiar with the statement about autism. Scores below a 3 indicated less familiarity with the statement about autism. As can be seen from Table 5.21, most of the respondents were somewhat to very familiar with the statements about autism. However there was a trend towards being less familiar with the last three items in the survey as follows:

18. Families with children on the autism spectrum experience lower levels of social support than families who have children with other special needs.

19. Couples with children on the autism spectrum have higher rates of divorce than couples who have children with other special needs.
20. There are books and training materials geared specifically for churches to meet the needs of families with children on the autism spectrum.

In order to see the range of responses, the scores on the autism awareness survey were summed so that each respondent was given a possible total score. The top possible score was 92, indicating the respondent was very familiar with all of the statements. The lowest possible score would have been 20, indicating the respondent was very unfamiliar with all of the statements.

The sum of scores ranged from 92 to 49 (Mean = 77.79, Median = 80.00, Mode = 92).

Figure 5.3 shows the trend of responses, with most of the responses scoring above 77.

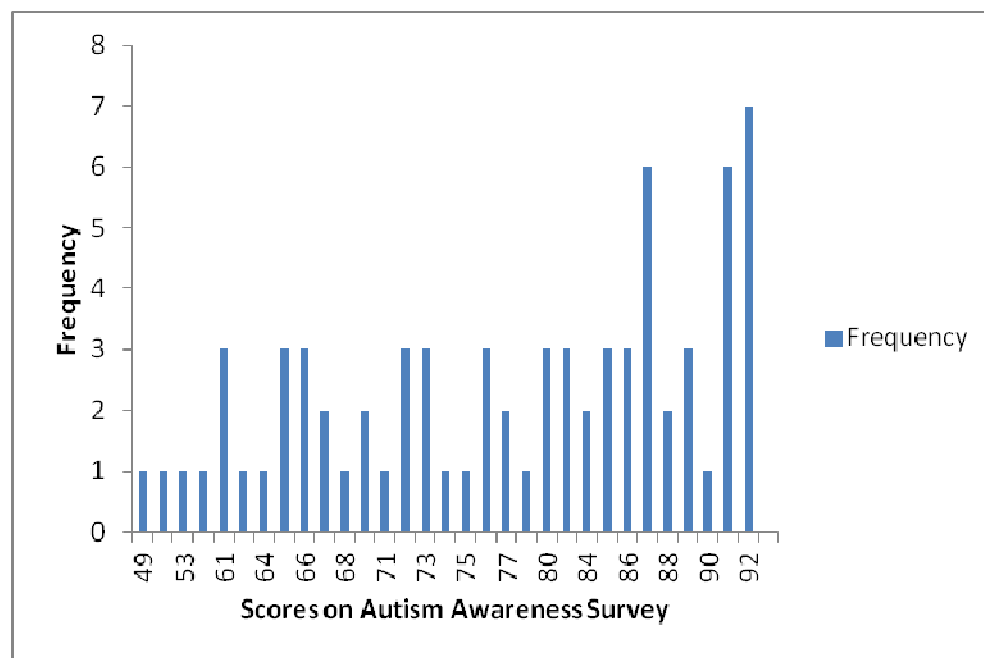


Figure 5.3 Distribution of summed scores for the Autism Awareness Survey

Using a median split, the summed scores were then divided into two categories of higher scores and lower scores. Higher scoring respondents scored from 80 to 92; lower scoring

respondents scored from 49 to 79. A chi-square test was performed to determine if there were any significant differences between high scores/low scores and certain variables from the church demographic questionnaire. Results of the survey did not differ significantly according to denomination  $\chi^2 (5, N = 125) = 2.86, p = .74$ , or the position of the staff member who answered the questionnaire  $\chi^2 (5, N = 125) = 3.28, p = .67$ . The differences in responses were not significant according to the number of full-time staff hired by the church  $\chi^2 (4, N = 75) = 9.13, p = .06$ . However, results differed significantly according to zip code  $\chi^2 (6, N = 75) = 15.48, p = .02$ , with the wealthy Southwest zip codes showing significantly higher scores. See Figure 5.4

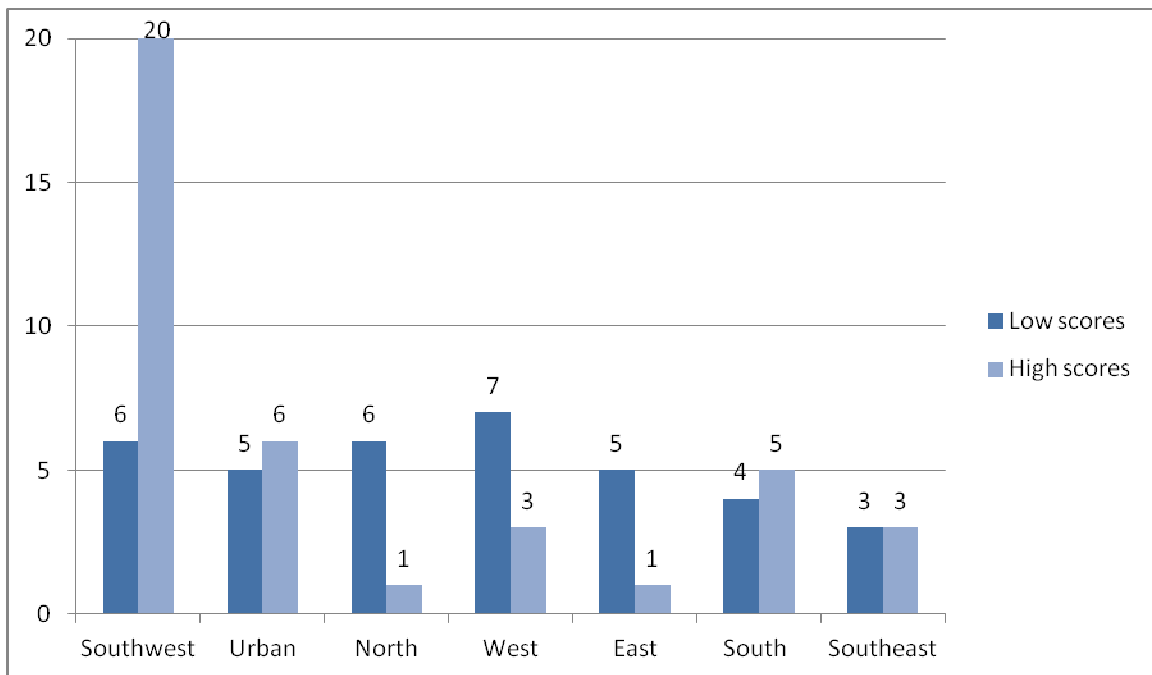


Figure 5.4 Low/High scores from autism awareness survey according to zip code group

Results also differed significantly according to congregation size, with the larger churches showing the highest degree of autism awareness  $\chi^2 (3, N = 75) = 12.26, p = .01$ . Churches that had children with special needs attending  $\chi^2 (1, N = 125) = 5.27, p = .02$ , or



children on the autism spectrum attending  $\chi^2(1, N = 125) = 11.77, p = .00$ , also scored significantly higher degrees of autism awareness.

The final question of the survey was, “Do you have any personal reflections about ministry to children with special needs that you would like to add?” About half ( $n = 61, 48.8\%$ ) of the respondents chose to give an answer to this last question. Responses were categorized according to themes, and a frequency table was generated to show the number of responses to each theme. Table 5.22 displays these results.

Table 5.22

Responses to Personal Reflections about Ministry to Children with Special Needs

Statement	Frequency	%
We have no time/no interest/no experience with such a ministry.	4	3.2
We are looking to expand our special needs ministry.	4	3.2
We have professionals in our church that help us.	5	4.0
These children are a blessing/gift to our church.	6	4.8
It is a growing need.	6	4.8
It is difficult to keep volunteers/run a special needs ministry.	6	4.8
We meet needs on a case by case basis.	7	5.6
We need more training in this area.	7	5.6
We have a biblical mandate to help those in need.	8	6.4
We are in the process of developing a special needs program.	8	6.4
Parents of children w/ special needs have a high amount of stress.	8	6.4
Parents are reluctant to accept or share diagnoses with churches.	9	7.2
We must support the whole family.	9	7.2
It is important to have a special needs ministry.	10	8.1
I have a family member with special needs.	11	8.8
Our goal is to show God’s love/make people feel welcome.	14	11.2

### Summary of Results from Research Questions 5 – 9

Quantitative data were obtained to answer questions 5 – 9 of this study. From a population of 1,100 churches, a phone survey was conducted on a stratified random sample of

300 churches in a mid-size metropolitan city in the South. There were 125 churches that responded to the phone survey. Of these, 75 churches responded to the Autism Awareness Assessment.

Churches were placed into the following categories to provide comparable groups: Liturgical, Mainstream, Evangelical, Baptist, Pentecostal, and Independent. Baptist was the largest group represented (28%). This was followed by Mainline (22.4%) and Evangelical (15.2%) churches.

Churches were also grouped according to zip code as a socioeconomic measure. The Southwest zip codes represented the highest property values in the metro area. This zip code category had the highest response rate from churches (32%).

Churches were also grouped according to congregational size: small (100 attendees or less – 24.8%), medium (101 – 500 attendees, 42.4%), large (501 – 1999 attendees, 24.8), and mega (2000+ attendees, 8%). In addition, churches were grouped according to the number of full-time staff they employed (Mean = 7.14, Median = 3, Mode = 1).

### **Research Question 5**

What characteristics of churches correlate with ASD programs? A significant relationship was found between zip code and churches providing programs for children with ASD. The wealthiest zip codes were more likely to have a child with ASD in the congregation, and therefore more likely to provide programs for children with ASD. Churches able to hire two or more full-time staff were more likely to have a child with ASD in the congregation and churches with five or more full-time staff were more likely to have programs for children on the autism spectrum. Also churches with a congregation size of more than 500 were more likely to have

programs for children on the autism spectrum. There was no statistically significant relationship between church denominational category and ASD programs.

#### **Research Question 6**

What proportion of churches has children on the autism spectrum in their congregations?

The majority of churches that responded to the survey had a child with special needs in their congregation (N = 87, 69.9%). About one-half this number had a child with ASD attending the church (N = 65, 52%). Of the churches that reported children with special needs attending, autism spectrum disorders was identified more than any other single diagnosis (N = 218).

#### **Research Question 7**

How did the church statistics on ASD compare to federal and state IDEA statistics?

Churches' numbers for autism rates were comparable with local and statewide IDEA statistics. However, churches reported a lower rate of attendance for children with special needs.

#### **Research Question 8**

What resources do churches provide for families who have children on the autism spectrum? Almost half of the churches that responded to the survey had made some type of change to their Sunday school programs to accommodate a child with ASD (N = 57, 45.6%). About one-third of churches implemented a buddy system in Sunday school (N = 43, 34.4%). Some churches provided special training for Sunday school workers (N = 31, 24.8%), informal respite for families (N = 24, 19.2%), counseling (N = 21, 16.8%), support groups (N = 14, 11.2%), or separate classrooms, (N = 14, 11.2%). Fewer churches provided formal respite programs (N = 6, 5.6%) or helped connect families with community resources (N = 5, 4%).

## **Research Question 9**

What degree of awareness do churches have about ASD? Of the 75 churches that answered the Autism Awareness Assessment, most respondents were somewhat to very familiar with the majority of the statements in the assessment. Respondents from larger churches showed the highest degree of autism awareness, as they were significantly more likely to have a child with ASD attending. The last three statements of the assessment showed a trend of respondents being less familiar with the information. Two of the statements were about families with children on the AS experiencing significantly lower levels of social support and higher rates of divorce than families who had children with other special needs. The other statement that indicated less familiarity on the part of staff members was about training materials being available to churches that would help meet the needs of families who had children on the AS. However, those who answered the autism awareness survey were more likely to come from larger churches in wealthier zip codes, have more full-time staff, and have children in the congregation with autism.

## **CHAPTER 6**

### **SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS**

This chapter discusses the implications of the research analysis. It begins with a summary of the study's purpose, literature review, theoretical framework, research questions, and methods. Next it offers an interpretation of findings from the study in the context of the theoretical framework and of each of the nine research questions. Finally, the chapter summarizes the implications these findings have for churches and gives recommendations for future research.

#### **Summary of Study Focus and Methods**

This section provides background information on the study. This includes study purposes, past research and theoretical framework. Also the research questions and study methods are summarized.

#### **Purpose of Study**

The purpose of this study was to understand the unique role of organized religion as a support system to families who have children with Autism Spectrum Disorder (ASD). Faith communities play a vital role in society and most have a theological duty to alleviate the stress of families with children with special needs and support healthy adaptation. Delimiting the scope of this study to Christian churches in a mid-size metropolitan area, this project sought to understand the level of support one family with a child on the Autism Spectrum experienced in the churches they have attended. Also, this study attempted to find to what degree clergy were aware of the

issues that surround families in coping with ASD, and how Christian churches responded to families who have children with a diagnosis of Autism Spectrum Disorder (ASD).

### **Summary of Literature Review and Theoretical Framework**

Personal faith and participation in organized religion is important for many families who have children with disabilities. When these families have positive experiences with their faith communities, they experience a greater degree of positive adaptation to the challenges of raising a child with special needs (McNair & Smith, 1998; Treloar, 2002; Tway, Connolly, & Novak, 2007). However, when these families are isolated, ignored and left out of their faith communities, they experience increased psychological distress (Speraw, 2006). Very few studies have been done on what types of support churches provide for these kinds of families. The few studies that exist indicate churches have a lack of awareness of the issues they face (Coulthard & Fitzgerald, 1999). Families with children who have ASD pose particular challenges for faith communities due to their behavioral challenges. In addition, no studies have been conducted on the particular challenges posed for faith communities by families who have a child on the autism spectrum, or how organized religion embraces the increasing number of families with children of autism.

This research project relied on family ecology theory for a theoretical framework (Bubolz, 1993). A model of this theory can be conceptualized as a series of four concentric circles with the family placed at the center:

1. The settings in the microsystem
2. The web of relationships in the mesosystem
3. The institutions and policies of the exosystem
4. The overarching culture of the macrosystem.

The family influences and is influenced by these systems. See Figure 6.1 for a visual model of this theory. Of particular interest to this project was how the church as a setting in the microsystem and a facilitator of relationships in the mesosystem impacts the functioning of a family who has a child on the autism spectrum.

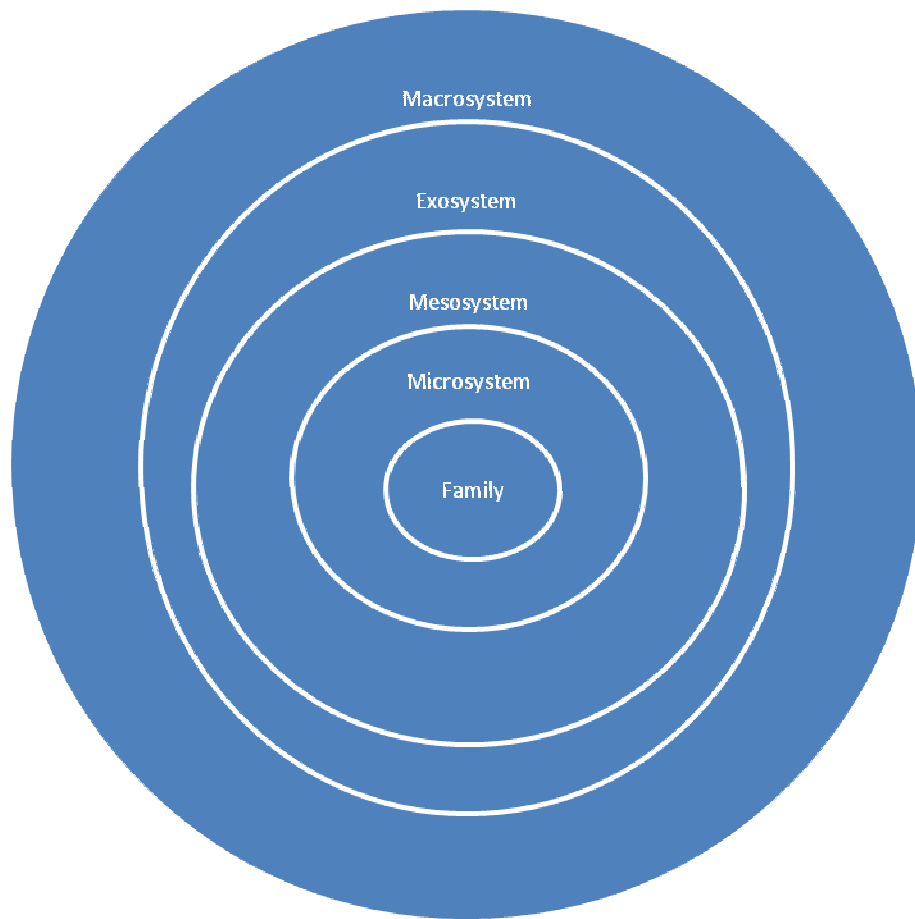


Figure 6.1 Visual model of family ecology theory

### **Summary of Methods**

The central question of the case study was, “What types of support does a typical church provide to the family when one of its members has been diagnosed with ASD, and what is the

impact of this support on the family?” From there, nine research questions were developed to explore this area.

1. What types of support is an ASD parent looking for from their church?
2. What kinds of impact does a family’s relationship with its church have on its ability to cope with the stress of having a child with ASD?
3. By what process does a church become aware of the need to support families who have children on the autism spectrum?
4. By what process does a church design programs to support families with a child who has ASD?
5. What characteristics of churches correlate with providing programs for families who have a child with ASD?
6. What proportion of churches has a program specifically to support families of children with ASD?
7. How do ASD prevalence rates of attendance in churches compare with regional and state IDEA statistics?
8. What resources are churches providing for families who have a child with ASD?
9. What is the degree of awareness of ASD among church staff?

In order to answer all nine research questions, this mixed methods study used a combination of qualitative and quantitative procedures. Questions 1 – 4 were answered using qualitative methods. Questions 5 – 9 were answered using quantitative methods.

To obtain qualitative data, interviews were done with members of one family and staff of the church where the family attends. Six interviews were obtained: four from the family (mother and three siblings) and two were from staff members at the church (the special needs



coordinator/Sunday school teacher and the Christian education director). Qualitative data were subjected to content analysis using constant comparative techniques.

For quantitative data, the study used a phone survey to obtain demographic information from churches and the level of awareness of ASD among church staff. A mid-size metropolitan area in the South was chosen and a population of 1,100 Christian churches was identified. The churches were stratified according to denominational affiliation to ensure a variety of denominational perspectives. From this population, a random sample of 300 churches was chosen. From this sample, 125 churches responded to the interview. These churches were grouped according to denominational category, congregational size, number of full-time staff members, and zip code (as a socioeconomic measure). Quantitative data were analyzed using SPSS to generate frequency tables and chi-square analysis.

### **Interpretation of Research Findings**

To better understand the results of this study, discussion begins by placing the family from the case study into the family ecology model and interpreting data in light of how the family's ecology changed after Jacob's behavioral symptoms became more pronounced. Next, other data from the study are explained in terms of how they answered Research Questions 1 – 9.

#### **Interpretation of Family Ecology Model Using the Smith Family**

At the center of the family ecology model is the Smith family, as a holistic entity. Before Jacob's AS symptoms developed, each of the family members related with each other and with those outside the family according to certain roles. These roles, always evolving and in a state of flux, created a pattern of relating that reflected the family's values. For example, Trisha and Sam had transitioned from the role of young married couple into the roles of mother and father of

three small children. Trisha would have described her family identity at that time as a “normal” young family, organized in a typical pattern of young families that she saw around her. See Figure 6.2.

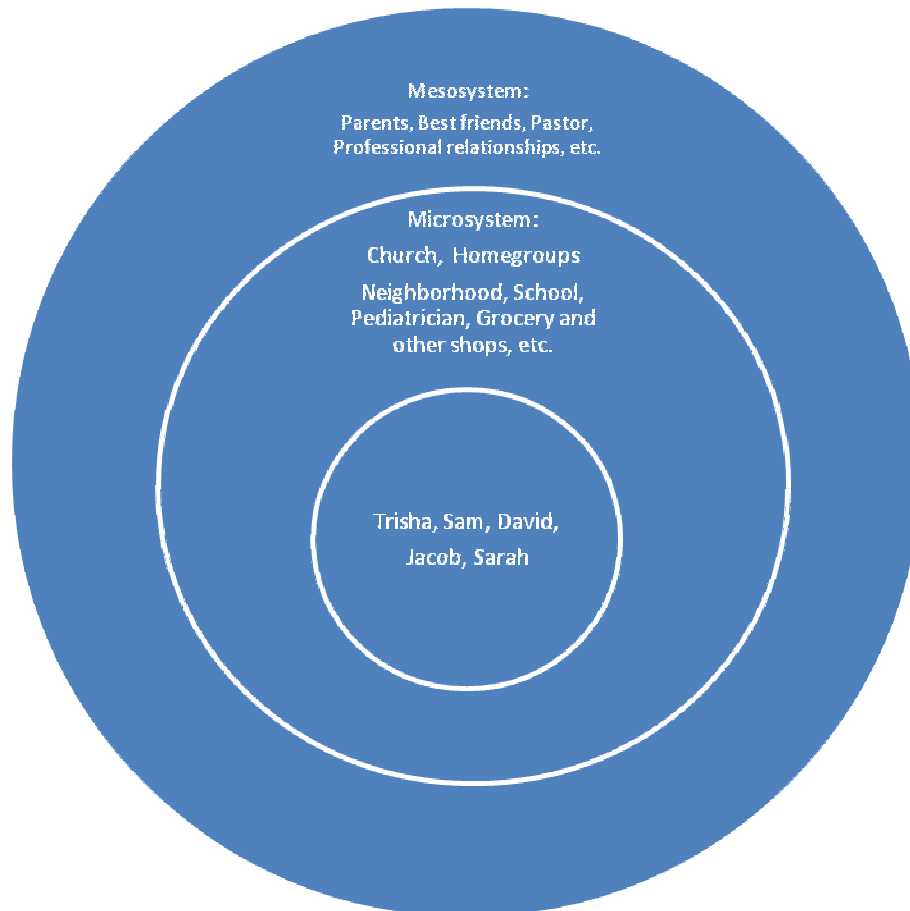


Figure 6.2 The Smith family micro- and mesosystems before ASD diagnosis

The family’s microsystem included what Trisha felt to be all the “normal” settings: home, church, school, grocery store and other places of business, pediatrician’s office, neighborhood, houses of grandparents and best friends, etc. Trisha felt welcomed, comfortable and well-connected with the web of relationships that comprised her family’s mesosystem. The church that her family attended was a hub for connecting with her most important relationships: her

parents and her best friends. The church provided the central opportunities in her life for social activities. In addition, the church operated as a place for worship and spiritual expression. All of these relationships and settings reinforced Trisha's identity as a "normal" family.

Findings from interview data revealed that as Jacob's symptoms became more prominent, the family transitioned to an identity as a family in temporary crisis. Trisha and Sam added the task of information gathering to their responsibilities as parents. In addition, they added settings to the microsystem that were mostly of a professional nature. Professional relationships were added to the mesosystem to determine what was wrong with Jacob. The family reorganized to focus on the member in crisis to see if treatment could be obtained to restore the family function to "normal."

For a while after Jacob's diagnosis of autism, the family continued in this emergency holding pattern as more resources were obtained for his treatment, with the expectation of finding a cure. More professional settings and professional relationships were added. During this time the family relied on their network of social relationships at church to sustain them.

However, what started as a temporary emergency pattern trying to reach status quo began to transition to a new set point for family functioning. Jacob's age-mates were continuing on a more neurotypical path of development. Slowly it became apparent to Trisha and Sam that the available treatments were not going to cure Jacob, and his behavioral challenges became more prominent.

When a child presents with significant deviation from neurotypical development, a family's roles and purpose are forced to change. Before the diagnosis, the Smith family's identity was that of a "normal" family. After Jacob's diagnosis of autism, they had to adjust to the identity of a family with a child who has special needs, a family that must deal with extremely

challenging behavior, sensory sensitivities, and communication impairments from one of its members. This change in identity was accompanied by many stressors and can be seen when viewing the changes that happened to the family's micro- and mesosystems.

The Smith family's web of friendships in the mesosystem changed as a result of decreased time and resources for socializing, and worries about how others viewed Jacob's severe tantrums. Jacob's treatment took time and resources, which before had been spent at church and other settings in the microsystem. Jacob's tantrums caused Trisha to worry that he would break something, or hurt someone. Trisha felt embarrassed and was concerned that others would assume these meltdown tantrums were the result of bad parenting. So, the family began to restrict the number of settings to which they would take Jacob; church, friends' houses, and grocery/shopping centers were no longer easily accessible.

This lack of easy accessibility caused Trisha and Sam to lose the primary hub of all their close, intimate relationships—the church. They stopped attending home groups, and Trisha lost her access to close, intimate friendships where she could unburden her heart. Eventually, they stopped attending church altogether. See Figure 6.3.

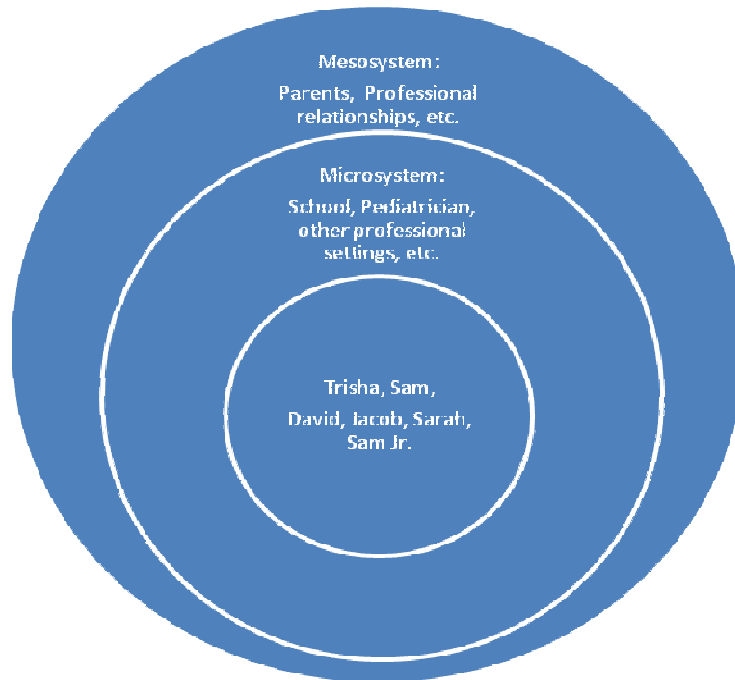


Figure 6.3 The Smith family micro- and mesosystems after ASD diagnosis

### Interpretation of Research Questions 1 – 2

In context of the family ecology model, what types of support is a parent with a child on the autism spectrum looking for from their church, and what kinds of impact does a family's relationship with its church have on its ability to cope with the stress of having a child with ASD?

Churches that are non-supportive to families with a child on the autism spectrum weaken the family's ecology. In the microsystem, the setting of church is no longer easily accessible due to behavioral and communication challenges and sensory sensitivities that a child on the autism spectrum may exhibit. This has a direct impact on the web of relationships in a family's mesosystem; families which no longer find their church to be welcoming and accessible lose the social and spiritual support that had previously been provided to them. This break in the family's

web of relationships often leads to an increased sense of isolation. And while some parents may continue searching until they find a church that welcomes them, others may drop out altogether and never rejoin a faith community.

Areas of support that a church may fail to provide include:

- Understanding that a child's tantrums may be a reaction to sensory sensitivities or a frustration from the lack of ability to communicate. When this happens, parents may feel judged or misunderstood, and may assume others blame the child's behavior on poor parenting.
- Understanding the ongoing grieving process which parents of children with profound special needs experience. When parents do not feel others understand their grief, they may feel that they must keep their burdens to themselves.
- Taking the initiative to find out what the church might expect from a child's diagnosis of autism and provide a welcoming, caring response. It seems to parents that they should not be expected to do all the explaining and advocating for their child's behaviors.
- Providing for the whole family, not just the child with autism. Parents and siblings have different areas of support.

Churches that provide support to families with a child on the autism spectrum strengthen the family's network of friendships. Social and spiritual support continues when a family is most in need, and the sense of isolation decreases. A supportive church provides:

- A contact person who communicates an exceptional feeling of welcome, love and acceptance to the family. Having such a person shows that the church is intentional in its ministry focus.

- Children's ministries leaders flexible enough to modify existing special needs programs or even to create an individual plan that will provide the support a child on the AS may need.
- Buddies/volunteers that are consistent and form a close bond with the family. An additional caring relationship strengthens the family's social support.
- Support for siblings. It is important for a church to recognize the needs of siblings as well. Siblings of children on the autism spectrum have different kinds of stressors from their peers.

### **Interpretation of Research Questions 3 – 4**

In context of the family ecology model, by what process do churches become aware of the need to support families who have children with an AS diagnosis? By what process do churches design programs to support these families? Churches become aware of the need to support families through strong relationships and good communication. These churches support a mesosystem of friendships that exists before the need arises. However, successful churches have more than just a network of good friends. The quality of relationships are such that either friends notice the family's struggles and see there is a need, or the family feels free to communicate their need. In addition, these churches foster an environment of good communication between the network of friends and the leadership structure of the church, so that church leaders are aware of the need and make it a priority to mobilize church resources to meet the need. These churches are able to adapt to a new identity when presented with a child on the autism spectrum. They become the church that embraces families who have a child on the autism spectrum and all the that the

behavioral challenges bring. Congregants are flexible to take on different roles in order to support the change in the church's identity.

Churches design successful autism ministries by building on the foundation of the trusting relationships they have formed with the families. By treating the parents as experts and by listening to their input, programs are designed to provide the type of support each family needs. Successful program designs take into account that children on the autism spectrum have a wide ranging set of needs; what works for one child will not necessarily work for another.

### **Interpretation of Research Question 5**

What characteristics of churches correlate with providing programs for families with a child with ASD? Wealthier churches with large congregations and plentiful full-time staff are more likely to have children on the autism spectrum attending. The church from the case study fits into these statistics (1,200 – 1,500 attendees; around 20 full-time staff positions.) These types of churches have more financial resources to support ministries to children with autism because these types of ministries are time-intensive and require someone to manage a large number of volunteers.

### **Interpretation of Research Questions 6 – 7**

What proportion of churches has a program specifically to support families of children with ASD? How do ASD prevalence rates of attendance in churches compare with IDEA statistics? About half of churches that responded to the survey had a child attending that had a diagnosis on the autism spectrum. These results indicate that nearly all churches can expect to see children with special needs appearing in their congregations, and should expect to have a role in meeting these needs. Children on autism spectrum are attending church at about the same rate as they are



attending public schools (around 1 %.) Autism was identified more than any other single diagnosis among churches that had children with special needs attending. This finding gives support to data that show the rise in autism prevalence rates (Centers for Disease Control and Prevention, 2009). However, this study did not account for the severity of any autism spectrum diagnosis in the demographic survey of churches. It may be that most churches have children with a mild or moderate autism spectrum diagnosis attending and that these children are much easier to integrate into Sunday school programs.

### **Interpretation of Research Question 8**

What resources are churches providing for families with a child who has ASD? Currently churches focus most of their efforts on providing programs during the Sunday school hour. A buddy system seems to be the most popular way to incorporate children on the autism spectrum into Sunday school. Some churches use peers as buddies; others use volunteers that they train, and some have access to members with professional training. Fewer churches provide separate classrooms for those children on the autism scale. Churches are not likely to provide respite, but when they do, they are more likely to provide some type of informal respite rather than a formal respite program. A few churches offer counseling, support groups, or provide a connection to other community resources.

It is not clear why churches choose to offer these specific programs, nor is it clear how effective these programs are at meeting the needs of families with children on the autism spectrum. One possible explanation for churches relying mostly on the buddy system is that they are not seeing as many children with more severe forms of ASD. Therefore the children are more easily incorporated into whatever special needs format the church already has developed. Also,

buddy systems may be an adaptation that represents the most efficient way for the church to organize its resources. Separate classrooms and formal respite programs do require a great deal more resources: adequate facilities, time, money and volunteers. This may mean that though qualitative results show parents need respite more than any other kinds of support, churches are not always aware of or able to provide the level of respite that parents need.

### **Interpretation of Research Question 9**

What is the degree of awareness of ASD among church staff? Most churches seem to have a high degree of awareness about autism. Respondents were familiar with basic information about autism—that it is not caused by bad parenting and that it is a neurological disorder. Most are aware of prevalence rates and basic diagnostic requirements (problems with eye contact, lack of social awareness, tantrums). However, churches were not as familiar with the higher levels of marital distress and lower levels of social support that parents who have children on the autism spectrum face. There was a lack of awareness among churches of the books and other training materials designed to help churches meet the needs of families who have children on the autism spectrum. This means that churches are probably not providing at least some of the support needed and could benefit from education about these areas.

### **Limitations of the Study**

The qualitative portion of this study was conducted on only one family. Therefore, there could be a concern about generalizing the results to other families (Ritchie & Lewis, 2003). The results of this study should be compared to other studies to assess whether or not the findings have transferability to other families (Corbin & Strauss, 2007; Ritchie & Lewis, 2003). Also, the questionnaire and survey used in this study were designed for this project and have not been

tested for reliability. Therefore, the answers may not produce reliable results. Also, respondents to the survey were more likely to come from a church that had children with autism attending, and the results in autism awareness may not represent their responses. In addition, respondents to the questionnaire and survey may have wanted to present information about themselves and their churches in the most positive light, gloss over inadequacies, or give inaccurate or false information. Finally, smaller churches were underrepresented in the survey as many of them only had answering machines and could not be contacted.

### **Recommendations for Practice**

It can be difficult for a church to meet all the needs that a family with a child on autism spectrum may have. But if churches are to fulfill their potential role as a source of support to families with children on the autism spectrum, they need to be aware of the key areas where such families need support and try to provide a setting where supportive relationships can be formed. Research findings support the need for three areas where churches can focus their efforts to reach families with children on the autism spectrum: relationships, resources, and respite.

One of the church's key areas of focus should be on strengthening or repairing relationships in a family's mesosystem (Woodgate, Ateah, & Secco, 2008). Churches can do this by:

- Providing a caring, warm point-person to help transition a family into the church (Poston & Turnbull, 2004)
- Developing a trusting relationship with the family so they feel welcome to come and share their needs (Poston & Turnbull, 2004)

- Viewing the family in a holistic way instead of only focusing on the child (Andrews, 1980; Crnic, 1983; Howell, 2010)
- Developing volunteers that are consistent and that will form a close relationship with the family (Poston & Turnbull, 2004)
- Providing opportunities for parents to do grief work (Speraw, 2006; Tarakeshwar & Pargament, 2001)
- Finding ways for the child with ASD to participate in the ministry of the church (McNair & Swartz, 1997; Poston & Turnbull, 2004)
- Connecting the family to community resources and advocacy groups (Flint, Atkinson, & Kearns, 2002; McNair & Smith, 1998; Poston & Turnbull, 2004; Treloar, 2002)
- Considering the ability of the church to assist families financially with the cost of ASD treatment (Norton, 1994)

Another key area of focus is on the church's resources. Smaller churches may not have the facilities, staff, and volunteer base for a large program. But such a church can assess what resources they do have. A successful ministry to families with children on the autism spectrum must have the following:

- Support of church leadership (pastor, CE director) as well as congregation (Tarakeshwar & Pargament, 2001)
- Organized, well-managed facilities
- Flexibility
- Growth that can be sustained by the rest of the church
- A view of parents as being experts on their child (Howell, 2010; Treloar, 2002)

- The ability to seek out additional professionals when necessary (Poston & Turnbull, 2004)
- The willingness to make modifications that accommodate behavioral/social/sensory challenges (Howell, 2010)
- A proactive stance on providing education to leadership and perhaps also to the congregation, so that church members will know what to expect if families with children on the autism spectrum unexpectedly begin to attend (Poston & Turnbull, 2004; Tarakeshwar & Pargament, 2001)

A final key area of focus is on providing some amount of respite to families with children on the autism spectrum (Howell, 2010; Poston & Turnbull, 2004; Tarakeshwar & Pargament, 2001). Churches that are smaller with fewer resources may approach respite programs differently than larger churches. One low-cost way to give support to families with children on the autism spectrum would be to start an informal network of respite care in the congregation so a parent could go to the grocery store, or attend a sporting event with other members of the family (Norton, 1994). Smaller churches can assist families in forming relationships with community and professional organizations or help families learn to advocate for their child. In addition, smaller churches in a community can band together to provide more types of programs than they could on their own.

Bigger and more expensive projects are more easily taken on by larger churches. In addition to formal respite programs, larger churches can more easily provide counseling and support groups. Also, larger churches may be able to assist a family financially and help shoulder the cost of needed therapy and opportunities for respite.

### **Recommendations for Future Research**

The results of this study are helpful but leave many more questions to be answered before there is a complete picture of churches' current and potential role as a source of support to families with children on the autism spectrum. Here are some suggestions for research that will help to fill in the picture of how churches can provide support to families with children on the autism spectrum.

This study model could be replicated in other cities using various faith traditions as the focus of study to see if results are similar. It would be beneficial to view results from studies that focus on prominent faith traditions such as Hindu, Jewish, or Muslim. In addition, there may be differences among Christian denominations that were not discovered due to the small sample size for some of the denominations.

The results of this study were heavily influenced by what larger churches are doing for children of the autism spectrum. Smaller churches may have been underrepresented due to lack of staff to answer the phone survey. These churches may provide effective support to families in their congregations.

There are different types of programs and models currently available that churches use to provide support to families with children on the autism spectrum. But it is not clear what types of programs are most effective at giving support. Churches and families would benefit from research that focuses on which programs are most effective.

This study did not make any distinction in the severity of autism spectrum diagnosis in the church survey. Families with children who have severe behavioral and sensory challenges on the autism spectrum may not attend church at the same rate as children with milder forms of

ASD. Therefore, it is possible that children with more severe forms of ASD are underrepresented in congregations.

A difference was found between those who responded to the autism awareness survey and those who did not. Respondents were more likely to have a child with autism attending their church. Therefore, the survey should be replicated in a way that could increase responses from those churches that do not have children with autism attending.

In addition, this study found a disparity between the percentage of children with special needs served in IDEA and the percentage of children with special needs in congregations. Children with special needs in general were seen in churches at much lower rates. This finding warrants further study to see if the rate of church attendance for families with special needs children is similar in other areas, and if so, what accounts for this disparity.

### **Summary of Study Findings and Recommendations**

Churches that are non-supportive to families with a child on the autism spectrum weaken the family's ecology. In the microsystem, the setting of church is no longer easily accessible due to behavioral and communication challenges and sensory sensitivities that a child on the autism spectrum may exhibit. This has a direct impact on the web of relationships in a family's mesosystem; families that no longer find their church to be welcoming and accessible lose the social and spiritual support that had previously been provided to them. This break in the family's web of relationships often leads to an increased sense of isolation. And while some parents may continue searching until they find a church that welcomes them, others may drop out altogether and never rejoin a faith community. Churches that provide support to families with a child on the autism spectrum strengthen the family's network of friendships. Social and spiritual support continues when a family is most in need, and the sense of isolation decreases.

Churches become aware of the need to support families through strong relationships and good communication with church leaders. Churches design successful autism ministries by building on the foundation of the trusting relationships they have formed with the families. Successful program designs take into account that children on the autism spectrum have a wide ranging set of needs and do not have a one-size-fits-all program.

Wealthier churches with large congregations and plentiful full-time staff are more likely to have children on the autism spectrum attending. About half of churches that responded to the survey had a child attending that had a diagnosis on the autism spectrum. These results indicate that nearly all churches can expect to see children with special needs appearing in their congregations. Currently churches focus most of their efforts on providing programs during the Sunday school hour; and while churches were familiar with basic information about autism, they were not as aware of the books and training materials that exist to help churches design autism programs. This may mean that churches are not aware of the ways they can meet the needs of these parents.

Recommendations for practice included ways to strengthen or repair relationships in the family's mesosystem, as well as ways to focus the church's resources. Ideas were given on providing increased amounts of respite for these families. Suggestions for future research were also included.



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## APPENDIX A

### INFORMED CONSENT LETTER FOR ADULT INTERVIEWS

## Informed Consent Letter for Adult Interviews

[Date]

Dear \_\_\_\_\_:

I am a doctoral student in the College of Education at the University of Tennessee at Chattanooga. I am conducting a research study to understand the way churches provide support for families who have children on the autism spectrum.

I am requesting your participation, which will involve a one-and-a-half hour audio-taped interview. Your participation in this study is voluntary. You may choose not to participate or to withdraw from the study at any time. The results of the research study may be published, but your name will not be used.

If you have any questions concerning the research study, please call me at 615-306-3946 or email me at [marsena-williams@utc.edu](mailto:marsena-williams@utc.edu). Or you may contact the chair of my dissertation committee, Dr. Hinsdale Bernard at 423-425-5460 or e-mail him at [Hinsdale-bernard@utc.edu](mailto:Hinsdale-bernard@utc.edu).

This research has been approved by the UTC Institutional Review Board (IRB). If you have any questions concerning the UTC IRB policies or procedures or your rights as a human subject, please contact Dr. M. D. Roblyer, IRB Committee Chair, at (423) 425-5567 or email [instrb@utc.edu](mailto:instrb@utc.edu).

Sincerely,

Marsena Webb  
644 Sugar Mill Dr  
Nashville, TN 37211

Please sign below to indicate your consent to participate in the interviews:

\_\_\_\_\_  
Name of interviewee

\_\_\_\_\_  
Date

APPENDIX B  
ASSENT FORM FOR CHILD



### **Assent Form for Child**

I have been informed that my parents have given permission for me to participate, if I want to, in a study concerning how the church supports our family with my brother's diagnosis of autism. My participation in this project is voluntary and I have been told that I may stop my participation in this study at any time. If I choose not to participate, it is completely okay and will not cause a problem in any way.

Signature and Date: \_\_\_\_\_

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact Dr. M. D. Roblyer, Chair of the Human Subjects Committee, Institutional Review Board at 423-425-5567. Additional contact information is available at [www.utc.edu/irb](http://www.utc.edu/irb)

APPENDIX C

PARENTAL CONSENT FOR SIBLING INTERVIEWS

## Parental Consent Letter For Sibling Interview

Dear Parent:

I am a doctoral student in the College of Education at the University of Tennessee at Chattanooga. I am conducting a research study to understand the way churches provide support for families who have children on the autism spectrum.

Your child's participation will involve an audio-taped interview that will last about an hour. Your participation, as well as that of your child, in this study is voluntary. If you or your child chooses not to participate or to withdraw from the study at any time, there will be no penalty. The results of the research study may be published, but your child's name will not be used. This research has been approved by the University Institutional Review Board.

Although there may be no direct benefit to your child, the possible benefit of your child's participation is being able to tell his/her story and voice his/her opinions.

If you have any questions concerning this research study or your child's participation in the study, please call me at 615-306-3946, or email me at [marsena-williams@utc.edu](mailto:marsena-williams@utc.edu).

Sincerely,

Marsena Webb  
644 Sugar Mill Dr  
Nashville, TN 37211

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I give consent for my child \_\_\_\_\_ to participate in the above study.

Parent's Name (print): \_\_\_\_\_

Parent's Signature \_\_\_\_\_ (Date) \_\_\_\_\_

If you have any questions about your rights as a subject/participant in this research, or if you feel you or your child have been placed at risk, you can contact Dr. M. D. Roblyer, Chair of the Human Subjects Committee, Institutional Review Board at 423-425-5567. Additional contact information is available at [www.utc.edu/irb](http://www.utc.edu/irb).

APPENDIX D

PARENTAL CONSENT FOR OTHER INTERVIEWS

## Parental Consent For Other Interviews

Dear Parent:

I am a doctoral student in the College of Education at the University of Tennessee at Chattanooga. I am conducting a research study to understand the way churches provide support for families who have children on the autism spectrum.

The participation of your child's (teacher/Sunday school teacher/church volunteer or staff member) will involve an audio-taped interview that will last about an hour and a half. Your consent for their participation is voluntary. You may withdraw consent for these interviews at any time. The results of the research study may be published, but your child's name will not be used. This research has been approved the University Institutional Review Board.

If you have any questions concerning this research study, please call me at 615-306-3946, or email me at [marsena-williams@utc.edu](mailto:marsena-williams@utc.edu).

Sincerely,

Marsena Webb  
644 Sugar Mill Dr  
Nashville, TN 37211

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I give consent for my child's teacher/Sunday school teacher/church staff or volunteer \_\_\_\_\_ to participate in the above study.

Parent's Name (print): \_\_\_\_\_

Parent's Signature \_\_\_\_\_ (Date) \_\_\_\_\_

If you have any questions about your rights as a subject/participant in this research, or if you feel you or your child have been placed at risk, you can contact Dr. M. D. Roblyer, Chair of the Human Subjects Committee, Institutional Review Board at 423-425-5567. Additional contact information is available at [www.utc.edu/irb](http://www.utc.edu/irb).

APPENDIX E  
AUDIO TAPE RELEASE FORM

### Audio Tape Release Form

I, \_\_\_\_\_, voluntarily agree to be audio taped during the interview being conducted by Marsena Webb, a student at the University of Tennessee at Chattanooga. I understand that the tapes will be used to gather information about families with children on the autism spectrum and such information will be used to complete Marsena Webb's dissertation. The tape will be kept for approximately one year and will be securely stored in a locked filing cabinet. Only the researcher and transcriptionist will have access to the tapes. After the data are collected and transcriptions are made, the tapes will be destroyed (by December 31, 2010).

\_\_\_\_\_  
My Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of the Investigator

\_\_\_\_\_  
Date

APPENDIX F  
PARENT INTERVIEW PROTOCOL



## **Parent Interview Protocol**

You were selected for this interview because you have been identified as someone who has a great deal to share about parenting a child with a diagnosis of autism. My research project focuses on the types of support families receive when they have a child on the autism spectrum. I am particularly interested in the support that churches provide.

1. When did you first notice your son was developing differently?  
Probes: What did you do?  
Who did you talk with to find answers? (Perform own research first?  
Go to pediatrician?)
2. What impact did the diagnosis of autism spectrum disorder have on you?  
Probes: Impact on marriage/family relationships  
Reaction from those closest to you  
Reaction from the church where you attended
3. Tell me about your level of involvement at the church where you attended at the time?  
Probe: Did anything change in your relationship with your church, or in your level of involvement?
4. At time of diagnosis in which areas did you need the most support?  
Probes: Emotional?  
Spiritual?  
Financial?
5. Who provided support for you at the time of diagnosis?  
Probes: Emotional support?  
Spiritual support?  
Financial support?
6. What are the most stressful aspects of raising a child who has ASD?
7. Where are your main sources of support for you and your family now?  
Probes: What forms of support have been most helpful?
8. What have been your experiences with other churches since the diagnosis of your son?  
Probes: What has been the most negative/difficult experience?  
What has been the most positive experience?
9. What types of support are you looking for in a church?
10. Why did you begin attending your current church?
11. What church activities do each member of your family most enjoy?
12. When you have felt unsupported by your church, how does that affect your ability to cope with the stress of ASD?
13. When you have felt supported by your church, how does that affect your ability to cope with the stress of ASD?

APPENDIX G  
SIBLING INTERVIEW PROTOCOL

## **Sibling Interview Protocol**

You were selected for this interview because you have been identified as someone who has a great deal to share about what it is like to have a sibling with a diagnosis of autism. My research project focuses on the types of support families receive when someone in the family has a diagnosis on the autism spectrum. I am particularly interested how the church provides support to your family.

1. How old are you?
2. Who are the people in your family and what are their ages?
3. Tell me more about \_\_\_\_\_.
4. What is the most difficult part of being \_\_\_\_\_'s brother/sister?
5. What is the best part about being \_\_\_\_\_'s brother/sister?
6. Tell me about your experience in attending church with your family.  
Probe: Have you ever attended a church where you did not feel welcomed?  
Do you feel welcomed and supported by the church you attend now?
7. What kind of support does this church offer to your brother? To your family? To you?
8. What types of support would you like to see from your church?
9. What do you like best about your church?
10. What do you like least about your church?
11. How has this church made a difference in how your family handles stress?

APPENDIX H  
CHURCH STAFF INTERVIEW PROTOCOL

## **Church Staff Interview Protocol**

You were selected for this interview because you have been identified as someone who has a great deal to share about a child with a diagnosis of autism. My research project focuses on the types of support families receive when they have a child on the autism spectrum. I am particularly interested in the support that churches provide.

1. How long have you attended this church?
2. What is your position here at the church?
3. How long have you been in this position?
4. Why did you decide to create an ASD program here at the church?
5. How did you begin the ASD program?
6. What programs does your church now provide that offers support for families with a child on the autism spectrum?
7. How many families with a child with ASD have begun attending your church since you began this ministry?
8. What important qualities does a volunteer need to have to work with a child who has ASD?
9. Tell me how you became acquainted with the X family.
10. How did you assess the best way to support this family?
11. Tell me about \_\_\_\_\_. What kind of a student is he?
12. Are there sensory factors that are important in teaching him?
13. What is his communication style?
14. What modifications have you used to provide Sunday school for this child?
15. How do you deal with behavior problems?
16. How do you communicate with the family?
17. Do this child and family participate in more than just Sunday school?
18. What has been the response from the family towards these efforts?

## APPENDIX I

### CHURCH DEMOGRAPHIC QUESTIONNAIRE

## **Church Questionnaire of Children with Special Needs in the Congregation**

I am a doctoral student in the College of Education at the University of Tennessee at Chattanooga. I am conducting a research study to understand the way churches provide support for families who have children on the autism spectrum.

The information from this questionnaire will be used to categorize the ways in which churches in this area are interacting with the special needs families in their congregations. There are three sections to this questionnaire: 10 demographic questions, 14 questions about knowledge of autism, and a comment section where you may add your personal reflections and experience of families with children with special needs.

This questionnaire will take about 10 minutes to complete.

The results of this questionnaire may be published, but your name and the name of your church will be kept confidential, shared with no one else, and are not included in this questionnaire. All results from this questionnaire will be reported anonymously.

Your participation is voluntary. You may choose to not to answer any questions and stop the questionnaire at any point.

This research has been approved by the UTC Institutional Review Board (IRB). If you have any questions concerning the research study, please call me at 615-306-3946 or email me at [marsena-williams@utc.edu](mailto:marsena-williams@utc.edu). Or you may contact the chair of my dissertation committee, Dr. Hinsdale Bernard at 423-425-5460 or e-mail him at [Hinsdale-bernard@utc.edu](mailto:Hinsdale-bernard@utc.edu).

If you have any questions concerning the UTC IRB policies or procedures or your rights as a human subject, please contact Dr. M. D. Roblyer, IRB Committee Chair, at (423) 425-5567 or email [instrb@utc.edu](mailto:instrb@utc.edu).

Your participation in this questionnaire represents your consent.

## I. Demographic Section

1. What is your job title or position in this church? \_\_\_\_\_

2. How many full-time staff is currently employed by this church? \_\_\_\_\_

3. What is the denominational affiliation of this church? \_\_\_\_\_

4. What is the ethnic makeup of this congregation?

\_\_\_\_\_ Primarily Caucasian

\_\_\_\_\_ Primarily African-American

\_\_\_\_\_ Primarily Hispanic

\_\_\_\_\_ Primarily Asian

\_\_\_\_\_ Other

Mixed ethnicity (please include ratio) \_\_\_\_\_

5. What is the average weekly Sunday/Saturday morning attendance this past year? \_\_\_\_\_

6. How many children currently attend this church? \_\_\_\_\_

7. Are you aware of any children with special needs that currently attend this church?

If so, how many? \_\_\_\_\_ How do you determine a child has a special need? \_\_\_\_\_

8. What types of special needs currently are represented in the children of this congregation?

Please answer yes or no to the following:

\_\_\_\_\_ Cancer

\_\_\_\_\_ HIV

\_\_\_\_\_ Traumatic brain injury

\_\_\_\_\_ CP

\_\_\_\_\_ Autism

\_\_\_\_\_ Down syndrome

\_\_\_\_\_ Deaf

\_\_\_\_\_ Blindness

\_\_\_\_\_ Muscular dystrophy

\_\_\_\_\_ Paralysis

\_\_\_\_\_ Epilepsy

\_\_\_\_\_ Mentally Challenged

\_\_\_\_\_ Chromosomal Abnormality (please specify: \_\_\_\_\_)

(i.e. Fragile X, Angelman's)

\_\_\_\_\_ Other (Please specify \_\_\_\_\_)

9. Does your church currently offer any programs/ministries for these families? \_\_\_\_\_ If so, please respond yes or no to the following:

\_\_\_\_\_ Counseling (Individual, Family, Support groups, Spiritual)

\_\_\_\_\_ Financial support

\_\_\_\_\_ Respite care (In home or at church)



\_\_\_\_\_ Sunday/Saturday school accommodations

\_\_\_\_\_ Buddy system

\_\_\_\_\_ Special training for workers

\_\_\_\_\_ Separate classrooms

\_\_\_\_\_ Physical modifications to SS rooms

\_\_\_\_\_ Address these issues from the pulpit

\_\_\_\_\_ Other (Please specify: \_\_\_\_\_)

10. Did you receive any formal training on the issues that surround children with special needs and their families? \_\_\_\_\_

**This completes the demographic section.**

APPENDIX J  
AUTISM AWARENESS SURVEY

## II. Autism Awareness Questionnaire

I am interested in finding out the level of awareness church staff have about autism. This last section of the survey contains 20 true statements about autism.

I will read each statement and you may respond with the following numbers:

4 – ***I am very familiar with this information.*** This means you have had training or read extensively about this area.

3 – ***I am somewhat familiar with this information.*** This means you have heard or read something about this in the media, but have not had specific training or read extensively about it.

2 – ***I am mostly unfamiliar with this information.*** This means you've heard something of this in passing.

1 – ***I am very unfamiliar with this information.*** This means the information is new to you.

Do you have any questions? Let's begin.

## AUTISM AWARENESS SCALE

<b>Statement</b>	<b>Rating Scale</b>			
1. Autism is not caused by bad parenting.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
2. The term 'autism spectrum' refers to a group of neurological symptoms that can range from severe to mild.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
3. The prevalence rate for autism is currently 1 in 110 children or perhaps even 1 in 91 children.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
4. Autism affects boys more than girls by a ratio of 2:1.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
5. Children on the AS may have limited eye contact.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
6. They may have difficulty making friends.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
7. They may have difficulty understanding common social rules.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
8. Children on the autism spectrum may 'parrot' back words	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
9. They may have difficulty understanding other people's gestures, body language and facial expressions.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
10. They may have limited or no creative play.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
11. Autism spectrum disorders may include finger- or hand-flapping.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
12. ...giggle fits that don't seem funny.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
13. ...meltdown tantrums when a routine is changed.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
14. Children on the autism spectrum may find the lights in a church to be painful to their eyes.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
15. ...the music in the church to be painful to their ears.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
16. ...hugs and other signs of affections may be irritating.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
17. Families that have children on the AS experience higher levels of stress and anxiety than families that have children with other special needs.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
18. Families that have children on the AS experience lower levels of support than families that have children with other special needs	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
19. Couples with children on the AS have higher rates of divorce than couples who have children with other special needs.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
20. There are training materials geared specifically for churches to meet the needs of families that have children on the AS.	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>

Do you have any personal reflections about ministry to children with special needs that you would like to add?

**This completes the autism awareness questionnaire.**

Thank you for your time and assistance with this project.

## VITA

Marsena Williams Webb was born in Augusta, Georgia, to Dr. and Mrs. Edward L. Williams. As a daughter and grand-daughter of ministers, Marsena graduated from Lee University (Cleveland, Tennessee) in 1988, with a Bachelor of Arts degree in psychology and a desire to work with underserved populations in mental health and in ministry. She then attended the Pentecostal Theological Seminary and graduated with a Master of Arts degree in Christian education. Afterwards, she worked for Hiwassee Mental Health Center (HMHC) as a behavior specialist with several of their programs (therapeutic preschool; behavior classroom with Bradley County school system.) She was also the director of HMHC's therapeutic preschool in Athens, Tennessee.

Marsena later attended Wheaton College Graduate School (Wheaton Illinois) where she first came in contact with families who had children on the autism spectrum through her work as a behavioral specialist using Applied Behavioral Analysis. She graduated with a Master of Arts degree in clinical psychology and moved back to Tennessee, working for several years as a counselor/social worker at the Smokey Mountain Children's Home. In 1997, she became a Licensed Professional Counselor with the state of Tennessee.

Currently, Marsena resides in Nashville, Tennessee, with her husband, Mark. She currently works for Mercy Children's Clinic as a therapist, and as a supervisor. She also teaches a course in *Ministry to Families with Special Needs Children* as an adjunct professor at the Pentecostal Theological Seminary.